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Explaining Alberta's rising mesothelioma rates

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Abstract

Although mesothelioma rates have been rising worldwide, little is known about mesothelioma trends in Alberta. This population-based descriptive study used Alberta Cancer Board Registry data from 1980 to 2004 to develop an age-period-cohort model of male pleural mesothelioma incidence rates over time. Both age and cohort effects are associated with incidence rates. The highest-risk cohort comprised men born between 1930 and 1939, reflecting widespread asbestos use and exposure beginning in the 1940s in Canada. We predict that 1393 Albertan men 40 years and older will die of pleural mesothelioma between 1980 and 2024; 783 (56.2%) of these deaths will occur between 2010 and 2024. The total number of mesothelioma deaths in Alberta will be higher when all age groups, both sexes, and all disease sites are included, with numbers likely peaking sometime between 2015 and 2019. In addition to the ongoing efforts that focus on eliminating asbestos-related disease in Alberta, the challenge is to implement surveillance systems to prevent future epidemics of preventable occupational cancers in Alberta.

Key words: mesothelioma, pleural neoplasms, incidence, asbestos

Introduction

Mesothelioma is a tumour of the mesothelium, the "thin lining on the surface of the body cavities and of the organs that are contained within them."¹ It most often occurs in the pleural cavity from inhaling asbestos fibres but can develop in the peritoneal cavity when asbestos fibres are swallowed. It is thought that up to 90% of male pleural mesotheliomas² and 60% of male peritoneal mesotheliomas² are caused by asbestos exposure, and that some 70-80% of mesotheliomas are related to occupational asbestos exposure.³

Asbestos comprises a heterogeneous group of magnesium silicate fibres, at least some of which increase mesothelioma risk.^{4,5} The durability of these asbestos fibre types allows them to remain in lung tissue for years and

may explain the elevated mesothelioma risk 20 to 50 years after first exposure.^{6,7} Mesothelioma incidence rates, which have been rising over the past 30 years,⁸⁻¹⁰ are expected to peak somewhere between 2010 and 2020 in Western Europe.¹⁰ During this time of increased rates, the economic cost of asbestos-related mesothelioma litigation and compensation may approach US\$200 billion in the United States¹⁷ and US\$80 billion in Europe.¹⁸

In 2003, 343 mesothelioma deaths were recorded in Canada, a 17% increase over 2000.¹⁹ Occupational asbestos exposure in Canada is most often associated with asbestos mining, which occurs primarily in Quebec,²⁰ thus drawing away attention from the potential for exposure in other provinces, including Alberta. However,

between 1920 and 1970, asbestos was commonly used in home and school construction as well as in manufacturing and the automotive industry, exposing groups such as construction workers and car mechanics to high levels of asbestos²¹ and potentially exposing most Albertans to some degree. The amount of illness created by asbestos use and removal in Alberta is currently unknown but could be substantial if large numbers of Albertans were exposed over a long time.

This study describes temporal trends in Alberta's mesothelioma rates from 1980 to 2004 and identifies the age, period and cohort effects underlying these trends. We then predict future mesothelioma incidence up to 2024.

Methods

Data sources

Mesothelioma incidence data from 1980 to 2004 were extracted from the Alberta Cancer Registry maintained by the Alberta Cancer Board. The Alberta Cancer Registry is a population-based, continuously updated database of all cancers diagnosed in Alberta; it is certified by the North American Association for Central Cancer Registries for its high-quality data and completeness in capturing at least 95% of Alberta's new cancer cases annually. Mortality data were obtained through Alberta Vital Statistics on place, cause and date of death. These are routinely linked to cancer registry data to identify patients' vital status (dead or alive). All subjects included in this study had malignant

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mesothelioma at diagnosis and were identified by the morphology code (M-905) following the International Classification of Diseases for Oncology (ICD-O-3).²² In addition to cancer morphology and type of mesothelioma (pleural, peritoneal or other), the following cancer registry information was extracted for each patient: date and place of birth; date, age and residence (Regional Health Authority) at diagnosis; date of death; gender; and vital status. All actual (or observed) and projected population figures were provided by Alberta Health and Wellness.²³

Statistical analysis

To facilitate temporal comparisons, rates were directly age-sex-standardized to the 1991 Canadian census population,²⁴ which is the standard used by most Canadian cancer agencies. We report average percentage changes in male incidence rates over the entire study period; average percentage changes in female rates were limited to 1987–2004 because the zero counts in 1980 and 1986 precluded the inclusion of the earlier years. To accommodate the possibility of changing mesothelioma incidence throughout the study period (i.e. incidence may be low initially, then increase before leveling off near the end of the study period), we chose to describe any changes in trends using joinpoint regression models which have been successfully applied in other cancer analyses.²⁵ The Joinpoint Regression Program version 3.3 developed by the National Cancer Institute was used to compute average annual percent changes (APC) with 95% confidence intervals (CI).

As much of the increase in mesothelioma occurred in men aged 40 to 94 years with pleural mesothelioma, we focused our statistical analysis on this age group. To describe rates over time, we used an age-period-cohort model with nine five-year age groupings (40 to 44, 45 to 49, through to 80+); five five-year periods (year of diagnosis) encompassing 1980 to 1984 up to 2000 to 2004; and 13 overlapping ten-year birth cohorts represented by respective means of 1900, 1905, up to 1960 (for example, the cohort 1905 comprised those born between 1900 and 1909). Because we expected a curvilinear shape to the graph, with rates peaking and then

decreasing, we chose to model the study data using regression splines.²⁶ Specifically, we opted to use natural splines because they are more stable in the tails than other commonly used splines.

The general form of the natural spline age-period-cohort model we used for the rate was log

$$(\lambda_{apc}) = \mu + f(a) + g(p) + h(c),$$

where a and p were the mean age and period for the five-year grouping, and c was the mean birth cohort for the ten-year grouping. For example, the mean age for the group 40 to 44 was 42.5; the mean date for the period 1980 to 1984 was 1982.5; the corresponding mean birth cohort (1940) was the difference between period and age, $c = p - a$. The term μ was an intercept, and the functions $f(a)$, $g(p)$ and $h(c)$ were the natural spline functions for age, period and cohort, respectively (after adjusting for the intercept term).

We tested a hierarchy of log-linear spline models^{27–29} to discern the effects of age, period and cohort on the prediction of mesothelioma incidence rates. The criteria for selecting the best of the hierarchy of tested models was a deviance score (i.e. the ratio of deviance to the degrees of freedom) close to one.

Since there was a positive association between age and pleural mesothelioma rate in men, we began with a model containing age and assessed improvements in this model upon the addition of drift, nonlinear period and nonlinear cohort effects. The drift effect combined the linear components of period; the cohort and nonlinear effects (also called curvature effects) were deviations from the linear trends.^{29–35,30} We used the same number of knots in each of the tested models: four knots for age (at 47.5, 57.5, 67.7, 77.5); two knots for period (at 1987.5, 1997.5); and six knots for cohort (at 1915, 1920, 1925, 1935, 1940, 1945). Although the choice of the number of knots has little effect on model fit,³¹ we attempted to choose the number of knots that maximized the fit of the model based on exploratory data analysis.

Using the best model to predict future incidence of mesothelioma up to the year 2025, we investigated when the number of cases is expected to peak in Alberta in two steps. In the first step, we estimated the future rate for each cohort through continuous extrapolation of our estimated cohort effects (i.e. estimated natural spline functions for each cohort) up to the year 2025. In the second step, we calculated the predicted number of cases for each cohort by multiplying the estimated rates from step one by the corresponding population estimates and summing all predicted cases over the cohorts to obtain the total number of predicted cases. All modeling used the R statistical package (Version 2.5.1)³² and the statistical testing was done at the 0.05 level of significance.

Results

Between 1980 and 2004, a total of 570 cases of mesothelioma were diagnosed in Alberta (Table 1), of which 487 (85%) were pleural mesotheliomas. Of the total 570 mesotheliomas, 470 (82%) occurred in men. Among the 487 pleural cases, 412 (85%) were in men. The majority of men (217 or 53%) with pleural mesothelioma were between the ages of 50 and 70. By the end of the study period, 445 (95%) men and 88 (88%) women had died.

Age-standardized incidence rates increased steadily throughout the study period, reflecting the increases in male pleural mesothelioma. The number of cases in women remained low (Figure 1) and constant (APC between 1987 and 2004 was 1.49; 95% CI of -5.40 to 8.89).

In men 60 years and older, the age-standardized rates of pleural mesothelioma increased 9.42% (95% CI of 6.91 to 12.00) per year over the study period. Age-specific rates more than doubled in those aged 60 to 69 years, but men 70 years and older showed the highest rate and largest increase between 1980 and 2004 (Figure 2).

Age-period-cohort analysis of male pleural mesothelioma

The incidence of male pleural mesothelioma generally increased with age group at each diagnosis period (Figure 3).

TABLE 1
Mesothelioma cases and age-specific incidence rate* (per 100 000) in Alberta, 1980 to 2004†

| Age group | Number of cases and incidence rate by five-year grouping (men with pleural mesothelioma) | | | | | | | | | | | |
|--------------|--|------------------------------|--------------------------|------------------------------|---------------------------|------------------------------|----------------------------|------------------------------|----------------------------|------------------------------|----------------------------|------------------------------|
| | 1980-1984 | | 1985-1989 | | 1990-1994 | | 1995-1999 | | 2000-2004 | | 1980-2004 | |
| | Count | Rate | Count | Rate | Count | Rate | Count | Rate | Count | Rate | Count | Rate |
| 20-24 | 1 (1) | 0.07 (0.14) | 0 (0) | 0.00 (0.00) | 1 (0) | 0.10 (0.00) | 0 (0) | 0.00 (0.00) | 0 (0) | 0.00 (0.00) | 2 (1) | 0.04 (0.04) |
| 25-29 | 0 (0) | 0.00 (0.00) | 0 (0) | 0.00 (0.00) | 0 (0) | 0.00 (0.00) | 0 (0) | 0.00 (0.00) | 0 (0) | 0.00 (0.00) | 0 (0) | 0.00 (0.00) |
| 30-34 | 0 (0) | 0.00 (0.00) | 2 (0) | 0.17 (0.00) | 0 (0) | 0.00 (0.00) | 1 (0) | 0.09 (0.00) | 0 (0) | 0.00 (0.00) | 3 (0) | 0.05 (0.00) |
| 35-39 | 3 (1) | 0.38 (0.24) | 1 (1) | 0.10 (0.20) | 0 (0) | 0.00 (0.00) | 1 (0) | 0.08 (0.00) | 1 (0) | 0.08 (0.00) | 6 (2) | 0.11 (0.07) |
| 40-44 | 2 (1) | 0.33 (0.31) | 3 (2) | 0.39 (0.51) | 2 (0) | 0.20 (0.00) | 6 (4) | 0.50 (0.66) | 3 (1) | 0.22 (0.15) | 16 (8) | 0.33 (0.32) |
| 45-49 | 4 (4) | 0.74 (1.43) | 4 (3) | 0.67 (0.98) | 5 (5) | 0.66 (1.29) | 4 (1) | 0.41 (0.20) | 13 (6) | 1.07 (0.97) | 30 (19) | 0.73 (0.91) |
| 50-54 | 8 (6) | 1.59 (2.29) | 11 (9) | 2.10 (3.34) | 4 (4) | 0.68 (1.35) | 15 (13) | 2.00 (3.42) | 12 (11) | 1.23 (2.22) | 50 (43) | 1.50 (2.52) |
| 55-59 | 5 (5) | 1.13 (2.27) | 14 (12) | 2.88 (4.81) | 17 (13) | 3.34 (5.02) | 14 (9) | 2.45 (3.12) | 20 (12) | 2.71 (3.22) | 70 (51) | 2.55 (3.67) |
| 60-64 | 6 (2) | 1.63 (1.13) | 10 (8) | 2.39 (3.90) | 17 (14) | 3.64 (5.96) | 31 (23) | 6.31 (9.35) | 14 (11) | 2.52 (3.97) | 78 (58) | 3.39 (5.09) |
| 65-69 | 8 (6) | 2.70 (4.31) | 12 (7) | 3.44 (4.29) | 15 (11) | 3.73 (5.76) | 27 (20) | 6.07 (9.13) | 28 (21) | 5.95 (9.05) | 90 (65) | 4.59 (6.88) |
| 70-74 | 4 (0) | 1.76 (0.00) | 8 (6) | 2.94 (4.90) | 21 (14) | 6.48 (9.65) | 23 (18) | 6.31 (10.74) | 36 (30) | 8.82 (15.38) | 92 (68) | 5.77 (9.25) |
| 75-79 | 3 (2) | 1.83 (2.68) | 8 (7) | 4.11 (8.31) | 14 (11) | 5.97 (11.10) | 14 (7) | 5.13 (6.08) | 33 (27) | 10.53 (19.73) | 72 (54) | 6.10 (10.59) |
| 80-84 | 4 (0) | 4.09 (0.00) | 1 (1) | 0.80 (1.92) | 5 (4) | 3.33 (6.78) | 13 (10) | 7.41 (14.81) | 24 (22) | 11.34 (26.78) | 47 (37) | 6.18 (12.26) |
| 85-89 | 4 (1) | 7.96 (5.16) | 0 (0) | 0.00 (0.00) | 0 (0) | 0.00 (0.00) | 1 (0) | 1.08 (0.00) | 5 (3) | 4.39 (7.84) | 10 (4) | 2.49 (2.81) |
| 90-94 | 0 (0) | 0.00 (0.00) | 1 (0) | 2.97 (0.00) | 0 (0) | 0.00 (0.00) | 1 (1) | 1.97 (6.05) | 2 (1) | 3.60 (6.66) | 4 (2) | 1.89 (2.95) |
| Total | 52 (29) | 0.61 (0.66) | 75 (56) | 0.75 (1.17) | 101 (76) | 0.91 (1.46) | 151 (106) | 1.20 (1.79) | 191 (145) | 1.29 (2.17) | 570 (412) | 1.00 (1.55) |

* age-standardized rate using total population in the denominator

† Numbers in parentheses represent males with pleural mesothelioma.

Both the age-cohort and age-period-cohort models had goodness-of-fit scores (or deviance scores) close to one, satisfying our criteria for a good fit between the data and the model. The curvature effect for period was found to be insignificant ($p = 0.62$). Overall, the age-cohort model fit the data well (deviance score close to one) and prompted us to fit spline functions for age and cohort.

Table 2 presents the observed and predicted numbers of pleural mesothelioma cases in 40 to 94 year-old men diagnosed in Alberta between 1984 and 2004. Each cohort-age combination in Table 2 consists of two numbers: the predicted count (top un-bolded number) resulting from the age-cohort model and the actual or observed count (bottom bolded number). For example, when people born between 1940 and 1949 (cohort: 1940 to 1949) reached age 40 to 44 years (age group: 40-44), there were two observed cases of mesothelioma compared to the 1.4 predicted cases. The observed counts corresponding to each cohort-age combination are similar to the predicted counts, indicating that, despite

the sparse data, the model adequately predicts mesothelioma cases. The age and cohort spline functions were reparametrized to improve interpretability.^{29,30} Specifically, we presented the age function as age-specific log rates of a reference cohort (Figure 4) and the cohort function as the log rate ratio compared to a reference cohort (Figure 5). The reparametrized age function shows the increase in mesothelioma rate as a cohort is followed over time (Figure 4). For example, in following the 1925 to 1934 cohort over time, we see that the rate per 100 000 increases from 9.1 (when aged 65 to 69 years) to 16.8 (when aged 70 to 74 years). Age-specific rates for other cohorts exhibit similar changes over time, with the highest rates pertaining to the 1930 to 1939 cohort. Figure 5 presents the rate ratio of mesothelioma compared to the reference (1925 to 1934) cohort. Specifically, compared to the 1925 to 1934 cohort, the 1930 to 1939 cohort has 1.13 times the risk of mesothelioma; all other cohorts have lower risk than the 1925 to 1934 cohort. We chose to use the 1925 to 1934 cohort as the reference because it is the middle cohort and therefore more

reliably estimated.³⁰ Although the birth cohort years overlap, the people in each cohort differ and therefore the increased risk is not attenuated by the overlap. Figures 4 and 5 also present 95% confidence bars which are fairly wide around some of the estimates due to exponentiation (the estimate and its standard error were originally on the log scale).

Predicted mesothelioma incidence

Based on our developed age-cohort model and assuming current trends and conditions continue in men 40 years and older, the number of pleural mesotheliomas is expected to increase to 247 cases between 2010 and 2014 and peak at 269 cases between 2015 and 2019. The number of cases will drop slightly to 267 between 2020 and 2024.

Discussion

The purpose of this study was to describe temporal variations in Alberta's mesothelioma rates and to explore how age, period and cohort effects explain these trends. Mesothelioma rates in Alberta appear to

FIGURE 1
Age-standardized incidence rates (/100 000) of mesothelioma by year of diagnosis and gender in Alberta, 1980 to 2004

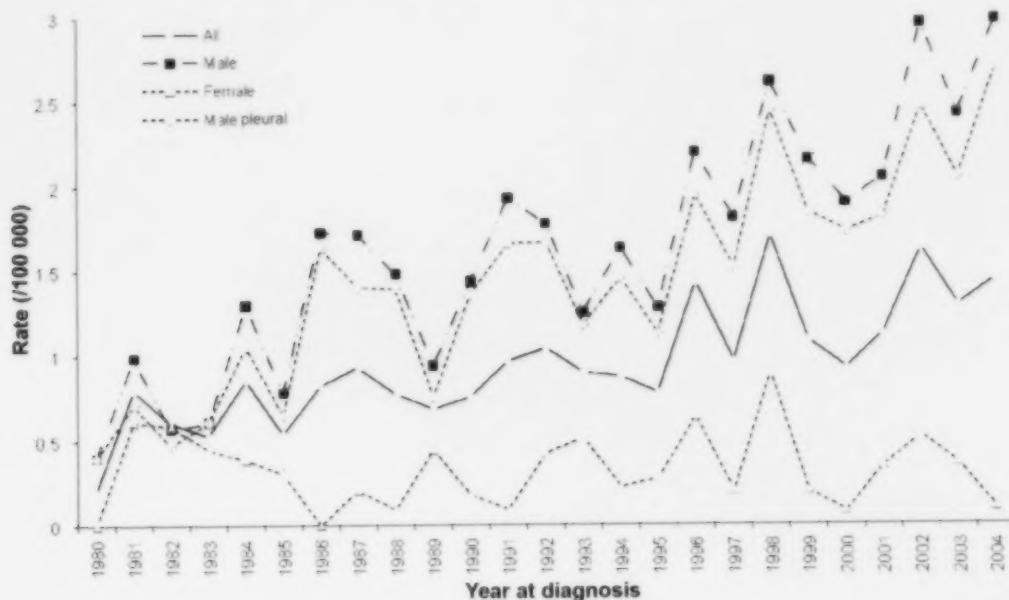


FIGURE 2
Age-specific incidence rates of male pleural mesothelioma in Alberta, 1980 to 2004

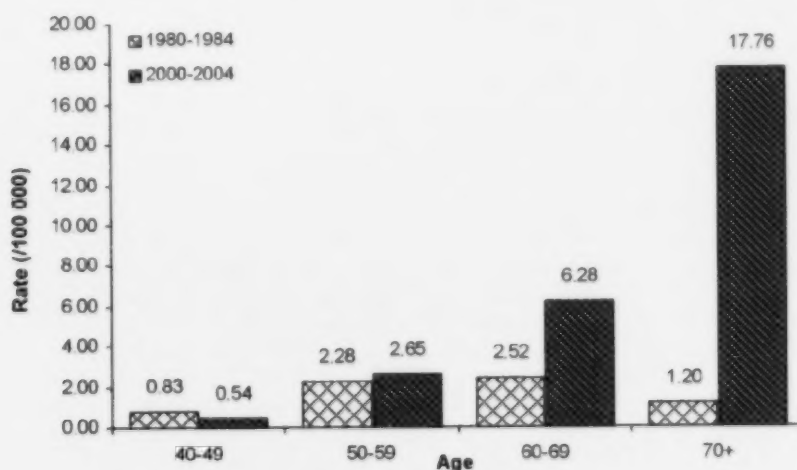


FIGURE 3
Age-specific incidence of male pleural mesothelioma by age group and year of diagnosis in Alberta, 1980 to 2004

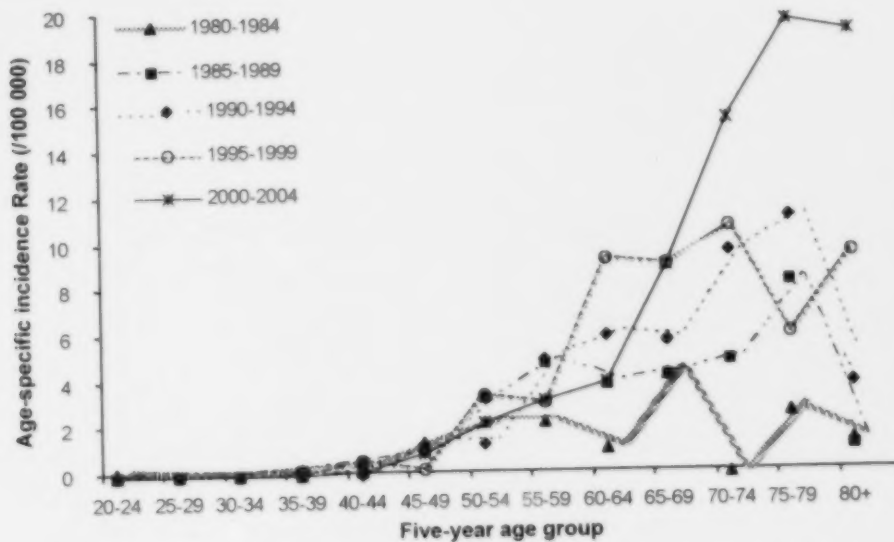


FIGURE 4
Age-specific incidence for birth cohort 1925 to 1934 based on age-cohort model

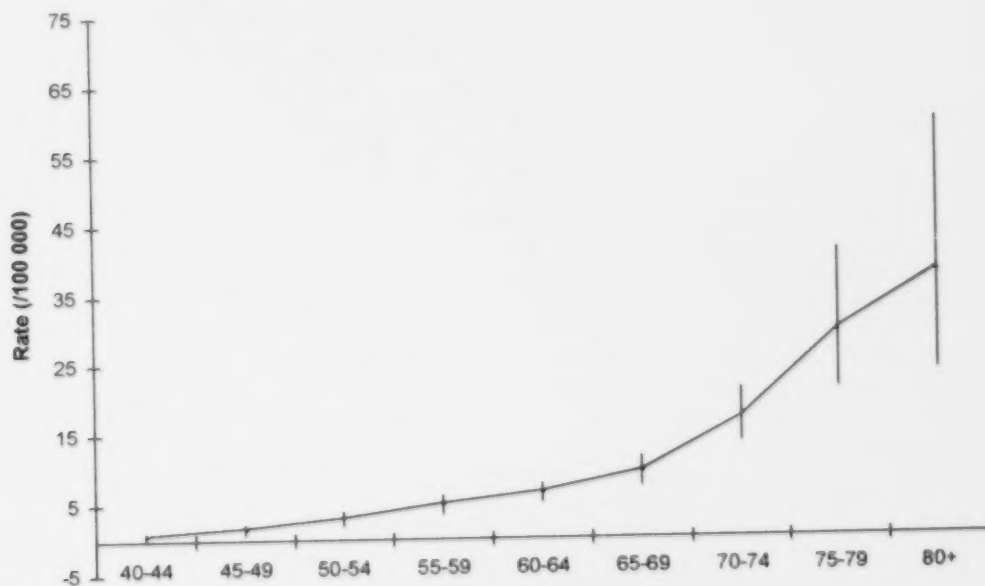
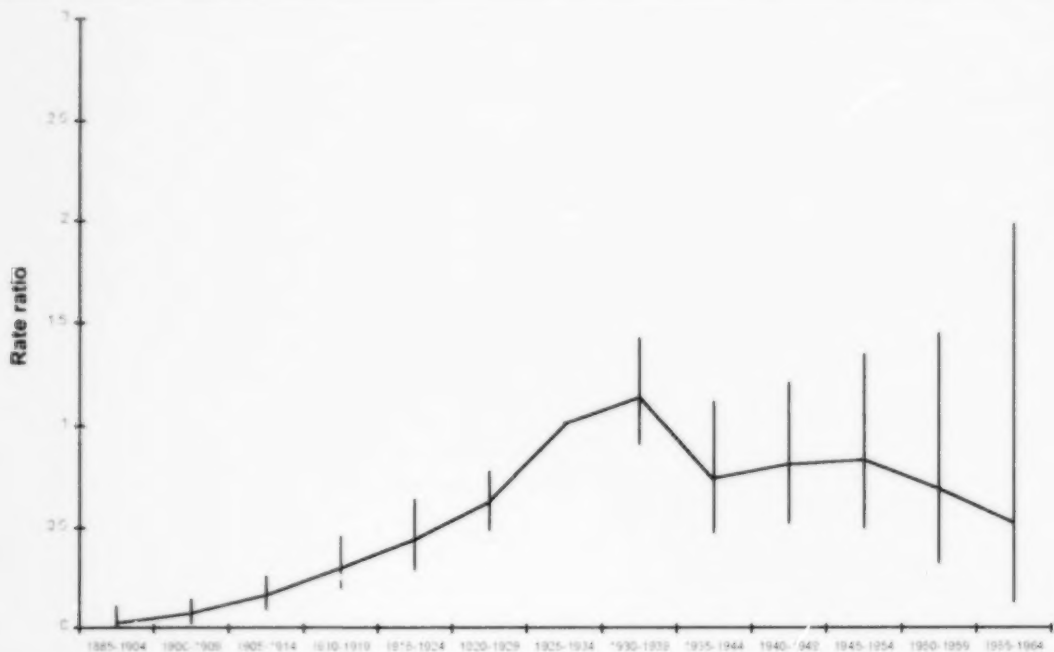


FIGURE 5
Incidence ratios relative to cohort 1925 to 1934 based on age-cohort model



be increasing in tandem with prevalent asbestos use in the 1970s and are expected to peak sometime between 2015 and 2019. The increase is driven primarily by pleural mesothelioma in older men. Between 1980 and 2025, male pleural mesothelioma will be the cause of death of an estimated 1393 Albertans over the age of 39 years; this is likely a conservative estimate considering asbestos-related illnesses are typically underreported.³³

We found both age and cohort effects predict mesothelioma rates. Consistent with other research,³⁴ we found a dramatic increase in cancer rates among men born between 1920 and 1935 (70 years and older) that is suggestive of asbestos exposure beginning in the 1940s and extending through to the mid-1970s when asbestos was commonly used in Canada. Our highest-risk cohort was the 1930-to-1939 one, differing somewhat from the highest-risk cohorts of other countries such as Britain (1920 to 1924),¹⁵ United States (1925 to 1929)¹⁵ and Europe (1945 to 1950).¹⁰ The significance of this difference is unclear and may be due to differences in latency period related

to exposure intensity and industry.³⁵ For example, the median latency for workers in the shipbuilding industry has been estimated at 52 years compared to 29 years for those in the insulation industry.³⁵

Although many countries worldwide have banned the import or sale of asbestos or asbestos products, Canada has opted to limit its use. Given the long latency period, banning asbestos now would not reduce the high number of cases expected in the next 15 to 20 years as incidence peaks sometime after 2010 to 2020.¹⁹ Our data predict cases will peak between 2015 and 2019, ten to 15 years after the United States (peak years of 2000 to 2004)¹⁵ and five to ten years after Great Britain (peak years of 2011 to 2015).¹³

The low and constant mesothelioma rates among women agree with trends observed in women in the United States;^{15,36} the age-standardized incidence rate in female Albertans averaged 0.3 per 100 000 between 1987 and 2004. The primary source of asbestos exposure for women has traditionally been environmental rather than

occupational. Prior to 1961, mesothelioma rates among men and women were similar in Canada.¹⁷ Rates among men began to rise after 1961 which, given the long latency period, would be expected if the cause was occupational asbestos exposure beginning in the 1940s. Rates among women, on the other hand, remained low and constant suggesting a baseline mesothelioma level exists and excess male rates are occupationally related. The origin of mesothelioma in women is somewhat controversial³⁸ and merits further study, particularly in terms of the potential for misdiagnosis of peritoneal mesothelioma as ovarian cancer.^{39,40}

This study has a number of limitations. Firstly, despite the well-established link between asbestos exposure and mesothelioma,³⁵ information on the source of exposure was not available for the majority of our study participants. Alberta's buoyant oil-based economy has attracted migrants who may have been exposed to asbestos while working in asbestos mining, shipbuilding or other high-risk industries in other Canadian provinces; immigrants may

have also been occupationally exposed in countries with lower safety standards prior to moving to Alberta. We have no estimate on how many high-risk adults have moved to Alberta during the study period, but the second component of our study investigating Workers' Compensation Board of Alberta (WCB) filing and compensation rates among the same cohort of subjects may provide some clarity in this regard.⁴¹ Secondly, our patient numbers may have been underestimated by as much as 30%⁴² for the early years of our study period; however, diagnostic accuracy has likely improved over time, and we expect any underreporting will have had relatively little impact on our trends or the reliability of our results for health services planning. Conversely, a tendency to misdiagnose a lesion as mesothelioma when it is actually a different cancer (overdiagnosis) has been noted in some exposed patient populations

such as asbestos miners in Quebec.^{42,43} However, similar high-risk occupations have not been identified in Alberta, and therefore we believe overdiagnosis is likely not a major problem in our results.

Our future research will focus on pinpointing sources of asbestos exposure in Alberta and on describing WCB compensation rates. Under Alberta's Occupational Health and Safety Act, mesothelioma is a reportable disease and therefore monitored by the Director of Medical Services. We know that so far less than half of our study subjects filed for WCB compensation. Those who did were commonly employed in the construction and automotive industries, typical sources of asbestos exposure between 1940 and 1970. Albertans' low filing rates are on par with findings from other provinces,^{39,44} and we have yet to examine who is uncompensated.

If present trends continue, we expect to see at least 783 new cases of pleural mesothelioma diagnosed in men 40 years and older in Alberta between 2010 and 2024. The total number of mesothelioma cases will be higher when combining all age groups, both sexes and all types of mesothelioma. Most of these cases will have been exposed to asbestos sometime after 1970, about 10 years after the causal link between mesothelioma and asbestos was generally accepted.⁴⁵ Although asbestos is not mined in Alberta, we still record a substantial number of mesothelioma diagnoses. The future challenge is to identify the sources of asbestos exposure in Alberta, because we now know that "prevention is the only cure for asbestos diseases."⁴⁶ With the frequent introduction of new chemicals and man-made or organic asbestos-like substitutes into the workplace, the broader challenge is to avoid future epidemics of preventable

TABLE 2
Total male pleural mesothelioma cases: observed* and predicted† by natural spline age-cohort model

| Cohort/age | 40-44 | 45-49 | 50-54 | 55-59 | 60-64 | 65-69 | 70-74 | 75-79 | 80+ |
|------------|----------|----------|-----------|------------|------------|------------|------------|------------|------------|
| 1885-1904 | | | | | | | | | 0.6 1 |
| 1900-1909 | | | | | | | | 1.3 2 | 2 1 |
| 1905-1914 | | | | | | | 2.7 0 | 3.8 7 | 5.9 4 |
| 1910-1919 | | | | | | 3.8 6 | 6.2 6 | 8.7 11 | 12.9 11 |
| 1915-1924 | | | | | 4.8 2 | 6.4 7 | 10.5 14 | 14.6 7 | 21.9 26 |
| 1920-1929 | | | | 6.1 5 | 6.4 8 | 10.6 11 | 17.1 18 | 24.5 27 | |
| 1925-1934 | | | 7.1 6 | 11.3 12 | 14.6 14 | 19.9 20 | 32.8 30 | | |
| 1930-1939 | | 3.9 4 | 8.3 9 | 13.3 13 | 17.3 23 | 23.9 21 | | | |
| 1935-1944 | 1 1 | 2.7 3 | 5.8 4 | 9.4 9 | 12.4 11 | | | | |
| 1940-1949 | 1.4 2 | 3.8 5 | 8.1 13 | 13.3 12 | | | | | |
| 1945-1954 | 1.8 0 | 5 1 | 11 11 | | | | | | |
| 1950-1959 | 1.8 4 | 5.2 6 | | | | | | | |
| 1955-1964 | 1.5 1 | | | | | | | | |

* bolded numbers – observed (bottom)

† unbolded numbers – predicted (top)

occupational cancers through instituting carcinogen-exposure surveillance systems and evidence-based policies.

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References

- Mesothelioma Glossary of Terms; 2007. Available from: <http://www.medicinenet.com/mesothelioma/glossary.htm>.
- Spirtas R, Heineman EF, Bernstein L, Beebe GW, Keehn RJ, Stark A, Benichou J. Malignant mesothelioma: attributable risk of asbestos exposure. *Occup Environ Med*. 1994;51(12):804-11.
- Goldberg M, Imbernon E, Rolland P, Gilg Soit Ilg A, Savès M, de Quillacq A, Frenay C, Chamming's S, Arveux P, Boutin C, Launoy G, Paire JC, Astoul P, Galateau-Sallé F, Brochard P. The French National Mesothelioma Surveillance Program. *Occup Environ Med*. 2006;63(6):390-5.
- McDonald AD, Case BW, Chung A, Dufresne A, Gibbs GW, Sébastien P, McDonald JC. Mesothelioma in Quebec chrysotile miners and millers: epidemiology and aetiology. *Ann Occup Hyg*. 1997;41(6):707-19.
- Hodgson JT, Darnton A. The quantitative risks of mesothelioma and lung cancer in relation to asbestos exposure. *Ann Occup Hyg*. 2000;44(8):565-601.
- Peto J, Seidman H, Selikoff IJ. Mesothelioma mortality in asbestos workers: implications for models of carcinogenesis and risk assessment. *Br J Cancer*. 1982;45(1):124-35.
- McDonald JC, Harris JM, Berry G. Sixty years on: the price of assembling military gas masks in 1940. *Occup Environ Med*. 2006;63(12):852-855.
- Marinaccio A, Montanaro F, Mastrantonio M, Uccelli R, Altavista P, Nesti M, Costantini AS, Gorini G. Predictions of mortality from pleural mesothelioma in Italy: a model based on asbestos consumption figures supports results from age-period-cohort models. *Int J Cancer*. 2005;115(1):142-7.
- La Vecchia C, Decarli A, Peto J, Levi F, Tomei F, Negri E. An age, period and cohort analysis of pleural cancer mortality in Europe. *Eur J Cancer Prev*. 2000;9(3):179-84.
- Peto J, Decarli A, La Vecchia C, Levi F, Negri E. The European mesothelioma epidemic. *Br J Cancer*. 1999;79(3-4):666-72.
- Gennaro V, Ugolini D, Viarengo P, Benfatto L, Bianchelli M, Lazzarotto A, Montanaro F, Puntoni R. Incidence of pleural mesothelioma in Liguria Region, Italy (1996-2002). *Eur J Cancer*. 2005;41(17):2709-14.
- Segura O, Burdorf A, Looman C. Update of predictions of mortality from pleural mesothelioma in the Netherlands. *Occup Environ Med*. 2003;60(1):50-5.
- Hodgson JT, McElvenny DM, Darnton AJ, Price MJ, Peto J. The expected burden of mesothelioma mortality in Great Britain from 2002 to 2050. *Br J Cancer*. 2005;92(3):587-93.
- McElvenny DM, Darnton AJ, Price MJ, Hodgson JT. Mesothelioma mortality in Great Britain from 1968 to 2001. *Occup Med (Lond)*. 2005;55(2):79-87.
- Price B, Ware A. Mesothelioma trends in the United States: an update based on Surveillance, Epidemiology, and End Results Program data for 1973 through 2003. *Am J Epidemiol*. 2004;159(2):107-12.
- Ilg AG, Bignon J, Valleron AJ. Estimation of the past and future burden of mortality from mesothelioma in France. *Occup Environ Med*. 1998;55(11):760-5.
- Carroll SJ, Hensler DR, Abrahamse A, Gross J, Ashwood JS, Sloss EM, White M. Asbestos litigation costs and compensation: an interim report. Santa Monica: RAND; 2002.
- Shah N, Williams A. Surviving the asbestos epidemic. In: *Insurance Digest (European)*. London: PricewaterhouseCoopers; 2001:14-8.
- Sharpe A, Hardt J. Five deaths a day: workplace fatalities in Canada, 1993-2005. Ottawa: Centre for the Study of Living Standards; 2006.
- De Guire L, Labrèche F, Poulin M, Dionne M. The Use of Chrysotile Asbestos in Quebec. Montreal: Institut national de santé publique du Québec; 2005.
- Cole D. Mesothelioma. Asbestos in Use Today. Available from: <http://www.davidcole.net/mesothelioma/asbestos/use.html>.
- Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. *International Classification of Disease for Oncology*. 3rd ed. Geneva: World Health Organization; 2000.
- Alberta Health and Wellness. Population Projections for Alberta and its Health Regions 2006-2035. Edmonton: Alberta Health; 2007. Available from: <http://www.health.alberta.ca/documents/Population-Projections-2006.pdf>
- Statistics Canada. 1991 Census of Canada. Ottawa; 1991.
- Kim HJ, Fay MP, Feuer EJ, Midthune DN. Permutation tests for joinpoint regression with applications to cancer rates. *Stat Med*. 2000;19(3):335-51.
- Heuer C. Modeling of time trends and interactions in vital rates using restricted regression splines. *Biometrics*. 1997;53(1):161-77.
- Holford TR. Analysing the temporal effects of age, period and cohort. *Stat Methods Med Res*. 1992;1(3):317-37.
- Clayton D, Schifflers E. Models for temporal variation in cancer rates. II: Age-period-cohort models. *Stat Med*. 1987;6(4):469-81.
- Carstensen B. Age-period-cohort models for the Lexis diagram. *Stat Med*. 2007;26(15):3018-45.

30. Clayton D, Schifflers E. Models for temporal variation in cancer rates. I: Age-period and age-cohort models. *Stat Med*. 1987;6(4):449-67.
31. Keele LJ. Semiparametric Regression for the Social Sciences. John Wiley and Sons, Ltd; 2008. p. 49-85. Available from: http://media.wiley.com/product_data/excerpt/17/04703199/0470319917-1.pdf.
32. R Statistical Package. Available from: <http://www.r-project.org>.
33. Lemen R. Asbestos Disease Awareness Organization Science Advisory Board Co-Chair. Asbestos Disease Awareness Organization Releases New Findings on Exposed Victims [Internet]. News release; 2007.
34. Sub-committee on the epidemiology of asbestos-related diseases in Quebec. The Epidemiology of Asbestos-Related Diseases in Quebec. Quebec: Institut Nationale de santé publique du Québec; 2004.
35. Marrett LD, Ellison LF, Dryer D. Canadian cancer statistics at a glance: mesothelioma. *CMAJ*. 2008;178(6):677-8.
36. Price B. Analysis of current trends in United States mesothelioma incidence. *Am J Epidemiol*. 1997;145(3):211-8.
37. McDonald AD, McDonald JC. Malignant mesothelioma in North America. *Cancer*. 1980;46(7):1650-6.
38. Smith DD. Women and mesothelioma. *Chest*. 2002;122(6):1885-6.
39. Payne JL, Pichora EC. Exploring the Burden of Occupational Cancer in Ontario: Focus on Mesothelioma (unpublished manuscript); 2007.
40. Bollinger DJ, Wick MR, Dehner LP, Mills SE, Swanson PE, Clarke RE. Peritoneal malignant mesothelioma versus serous papillary adenocarcinoma. A histochemical and immunohistochemical comparison. *Am J Surg Pathol*. 1989;13(8):659-70.
41. Cree M, Lalji M, Jiang B, Carriere KC. Under-reporting of Compensable Mesothelioma in Alberta. *Am J Ind Med*. 2009;52(7):526-33.
42. Bourdès V, Boffetta P, Pisani P. Environmental exposure to asbestos and risk of pleural mesothelioma: review and meta-analysis. *Eur J Epidemiol*. 2000;16(5):411-7.
43. McDonald JC, McDonald AD. Epidemiology of mesothelioma from estimated incidence. *Prev Med*. 1977;6(3):426-42.
44. Martin CW, Noertjojo K, Dunn CT. Mesothelioma claims at the Workers' Compensation Board of British Columbia, Canada, 1987 - 2002. Available from: http://www.worksafebc.com/health_care_providers/Assets/PDF/poster-presentations/mesothelioma_claims_WCB.pdf.
45. Wagner JC, Sleggs CA, Marchand P. Diffuse pleural mesothelioma and asbestos exposure in the North Western Cape Province. *Br J Ind Med*. 1960;17:260-71.
46. Asbestos Disease Awareness Organization (ADAO). Asbestos Disease Patients are Younger. News release; 2007.

An intersectoral network for chronic disease prevention: the case of the Alberta Healthy Living Network

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Abstract

Chronic Diseases (CDs) are the leading causes of death and disability worldwide. CD experts have long promoted the use of integrated and intersectoral approaches to strengthen CD prevention efforts. This qualitative case study examined the perceived benefits and challenges associated with implementing an intersectoral network dedicated to CD prevention. Through interviewing key members of the Alberta Healthy Living Network (AHLN, or the Network), two overarching themes emerged from the data. The first relates to contrasting views on the role of the AHLN in relation to its actions and outcomes, especially concerning policy advocacy. The second focuses on the benefits and contributions of the AHLN and the challenge of demonstrating non-quantifiable outcomes. While the respondents agreed that the AHLN has contributed to intersectoral work in CD prevention in Alberta and to collaboration among Network members, several did not view this achievement as an end in itself and appealed to the Network to engage more in change-oriented activities. Managing contrasting expectations has had a significant impact on the functioning of the Network.

Key words: chronic diseases, intersectoral network, qualitative research, Alberta Healthy Living Network

Background

Chronic diseases (CDs) are associated with 60% of all deaths and 46% of the burden of disease worldwide.¹ Recent reports and studies describe CDs as threatening health systems and economic stability around the world,² partly because the human and economic toll associated with CDs is expected to increase substantially in the next two decades.³ In Canada, the total cost of illness, disability and death due to CDs was estimated to be over \$45 billion in 2004.⁴ The societal cost for several CDs (heart disease, chronic obstructive pulmonary disease, diabetes and lung cancer) for people over 20 years of age was \$1.07 billion in Alberta in 2000, with

hospital and physician costs accounting for about 80% of the total. Lost income from premature death in that one year was estimated at \$13.3 million and, if extrapolated over the average working life to age 65, would amount to \$184 million.⁵

Chronic disease experts have long maintained that dealing effectively with CDs, individually or collectively, requires multifaceted approaches involving multiple strategies and sectors. The World Health Organization (WHO) calls for comprehensive, integrated and strategic approaches in dealing with CDs.^{4,6,7} A comprehensive approach involves 1) simultaneously supporting population-level health promotion and disease prevention

programs; 2) actively targeting groups and individuals at high risk; 3) maximizing population coverage with effective treatment and care; and 4) systematically reducing inequalities in health. An integrated approach on the largest scale means simultaneously targeting risk factors, underlying determinants of health and opportunities for disease prevention common to major CDs. The approach is strategic in that it has an impact on more than one disease.⁸

A comprehensive and integrated approach can also be applied to single diseases or risk factors. In Canada, an integrated approach to a single disease was first realized through the Canadian Heart Health Initiative (CHHI), which implemented community-based cardiovascular disease (CVD) prevention programs for 20 years from 1986 with funds matched by the federal government.

In Alberta, the response to the CHHI was the Alberta Heart Health Project, designed to explore the process of capacity building for heart health promotion within regional health authorities.⁹ While the project helped several authorities start CVD prevention initiatives, it has not led to sustainable investments in health promotion.¹⁰ Its legacy is that several key Alberta Heart Health Project members and promoters used its momentum to launch the Alberta Healthy Living Network (AHLN, or the Network) in 2002.⁹

The AHLN is supporting leadership for integrated, collaborative action to promote

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health and prevent CDs in Alberta.¹¹ Network members define an "integrated approach" as being multisectoral, multi-strategic, multi-disease and multi-risk factor, while simultaneously engaging a variety of instruments (appropriate legislation, health system reform) and players (local communities, health authority and government policy makers, non-governmental organizations, the private sector). The initial focus of the AHLN was on three risk factors common to CDs—unhealthy eating practices, tobacco use and physical inactivity—and their underlying determinants of health.¹²

In February 2008, the AHLN consisted of 93 diverse member organizations, some of which were outside of the health sector. Federal and provincial governments, regional health authorities, non-profit organizations, professional organizations, the research community, Aboriginal groups and other regional relevant networks were represented.¹² With this composition and mandate, the AHLN provides an opportunity to better understand how to apply an integrated approach to CD prevention using a network mechanism.

There exists a growing body of sociological literature about organizational networks. According to Scott,¹³ a wide range of motives exists to power the development of network forms. One of the main motives is the desire to enhance organizational learning. This is especially true in the case of strategic alliances, or "partnerships," a network form that is growing in popularity among knowledge-based organizations. However, Huerta et al.¹⁴ note that, in the case of health care networks, we still have little empirical information to understand what networks are, what they do and whether they achieve their stated goals—in this case, truly making a difference in the delivery of care and the maintenance of health. The authors conclude that there is a need for more empirical research to demonstrate how networks generate both challenges and opportunities for the participating

organizations. A similar conclusion applies to networks and alliances in the field of health promotion. A number of papers have proposed conceptual models (e.g. coalition theory) and/or tools (e.g. surveys based on the Diagnosis of Sustainable Collaboration model) for understanding interorganizational relationships and collaboration,^{15,16} but there are still few empirical demonstrations.¹⁷⁻²⁰ Overall, the conviction that partnership is a superior way of working in health promotion is still not clearly supported or refuted by the empirical literature.²⁰

So far, only one peer-reviewed paper about the AHLN has been published. That study examined whether partnership ties among the Network members influenced organizational perceptions of financial support.²¹ The authors argue that such perceptions are affected not only by organizational characteristics but also by a group's position in a network. They conclude that network contexts can influence the way that organizations perceive their environment and the actions they may take in light of such perceptions.

In this qualitative study, our objective was to better understand the perceived benefits and challenges associated with the implementation of the AHLN. This article will not systematically report on all of the AHLN's activities but rather will focus on the experiences of key Network members.

Methods

Data collection

We conducted 15 semi-structured interviews with key Network members in 2007 and 2008. The participants supported or directly contributed to the work of the AHLN and actively participated in one of the Network's committees or working groups.* The interviews lasted an average of 75 minutes and were audio-recorded. The initial interview guide included open-ended questions about the role of the AHLN, the functioning of the Network (committees

and working groups) and the perceived benefits and challenges associated with the implementation of the AHLN. (Please see Appendix for the interview questions.) Further clarifying and probing questions were added during the study process based on an iterative analysis of the collected material. Ethical approval was obtained from Health Canada's Research Ethics Board, and all participants provided informed consent before the interview.

Data analysis

The interviews were transcribed verbatim, and then coded and analyzed with the support of NVivo 8 software.[†] The coding tree was developed through an iterative open-coding process.²² Subsequent analysis involved axial and selected coding to explore interconnections between existing categories and subcategories. Finally, an immersion/crystallization approach²³ was used to identify and articulate the themes and patterns emerging from the empirical dataset. All references to opportunities and challenges associated with the development and implementation of the AHLN were identified, coded, and aggregated into themes. These themes were given tentative titles and grouped with demonstrative quotes from the interviews along with preliminary interpretations. The initial categories and patterns were tested and revised during the data collection process until saturation.

Results

Two overarching themes emerged from the data. The first theme relates to the perceived role of the AHLN; the second focuses on the perceived contributions of the AHLN and how to measure them. When discussing the role of the AHLN, respondents offered contrasting views about the extent to which the Network should be action- or advocacy-oriented and about what that would actually mean in practice. All respondents shared the same concerns about the challenge of defining and agreeing on the role of the Network

* Seven Working Groups were formed to address the seven priority strategies of the AHLN (see table 1) and accomplish specific actions (e.g. produce documents that can guide/facilitate integrated collaborative action) as directed by the Coordinating Committee.

† A computer assisted qualitative data analysis software (CAQDAS) like NVivo 8 1) helps automate and thus speed up the coding process and 2) provides a more complex way of looking at the relationships in the data.

TABLE 1
Areas of focus and priority strategies of the AHLN

| Areas of focus | Priority strategies for integrated action |
|--------------------------|--|
| Healthy eating | Partnership development and community linkages |
| Active living | Awareness and education |
| Tobacco-free environment | Healthy public policies |
| | Surveillance |
| | Best practices |
| | Research and evaluation |
| | Health disparities |

and about the necessity of measuring its impact. Demonstrating the added value of the AHLN was seen as a key challenge.

Developing a common vision about the role of the AHLN

The publication in 2003 of the *Alberta Healthy Living Framework*¹¹ (updated in 2005), was seen by all respondents as a key achievement of the Network. The *AHLN Framework*¹¹ describes the objectives and mission of the AHLN and its areas of focus and priority strategies (Table 1). Yet, several respondents feel that in "real life" (e.g. in meetings) the purpose and role of the Network is still unclear, whether it is to create "new" work or only support members' existing work:

[I]t is ... hard ... managing the expectations. There are the ones that say, "It is strictly a network and [a] network is all it's ever been and should be. It's an opportunity to get together and share ideas and know what each other is doing [*sic*]." And there are others who say, "No, we should be accomplishing things." ... somewhere in between, that is where we probably need to be, but right now we seem to have expectations that sort of cover the whole spectrum.

The areas of mental health and injury prevention have been progressively added to the original priority areas of tobacco use, nutrition and physical activity. Most respondents saw the broadening scope of the AHLN as bringing both new opportunities and new challenges:

[W]hen we started out it was very clear it was nutrition, physical activity and tobacco. And then it became very broad and it became very wellness-oriented, so I think that has been good in a lot of ways ... but it also dilutes things a bit ... you have too many different perspectives about how things should move forward ... [T]he good side of it, though, is that it does bring more players to the table as well. And, ultimately, I hope it would give you a greater impact if you have more partners involved in a broader approach to things.

Discussions about the role of the AHLN have attempted to clarify whether or not it is an "action-oriented" network and what "action" means. Respondents agreed that, so far, the Network has played more of a role in communication and coordination than in "action." A frequently cited example was the development of "common and integrated health messages":

[T]he issue of common messaging—I think that's a role that the AHLN can [play]. If we can come up with some common messages that all the different sectors and all the different organizations agree to [*sic*], then we can use those to inform professionals—health professionals and non-health professionals as well ...

While all the respondents agreed that developing "common health messages" was very valuable, many had expected that the

AHLN would also be active in supporting community-based initiatives:

I think we have to get down at [*sic*] the grass roots [level] and, you know, help community networks develop ... that has to come from the bottom up ... but the Network can support that work ... And we are not doing that. And in my opinion, unless we do that, the Network is never going to survive. You have to create the demand throughout the whole province for the need for that kind of thing to continue. ... That's where our gap is ...

The necessity to "create things" and to be "visible" also stems partly from the fear that members from the nongovernmental sector will lose interest in the AHLN if the work remains focused solely on coordination and communication:

I think that the grass roots organizations that are dedicated to socio-economic determinants of health may well lose interest around that. Well, we may lose them if we don't figure it out pretty soon.

According to some of the respondents, the challenges associated with identifying tangible deliverables may explain why at least two of the seven working groups are considered mostly "inactive".[†] Several interviewees associate the (growing) lack of engagement within the Network to the challenges of defining what actions are expected from the AHLN.

† At the time of data collection, in 2007, the working group on "healthy public policies" and the working group on "research evaluation" were considered "inactive".

Some of the respondents also identified policy change as another type of action that should be part of the Network's mandate and mission, especially since the AHLN has a Healthy Public Policies Working Group.

I believe in the Network. ... I do think we have been and can be an effective voice in the future. I do think we are going to have to look at ... the whole true health promotion model and that means influencing policies, looking at the social determinants of health, the whole disparity issue.

The prospect of influencing policies has been linked to "policy advocacy," a controversial subject among respondents. Should advocacy be part of the AHLN's mission? Some respondents were adamantly in favour: "Advocacy for political change ... is needed the most. And I really think that that should be a strong role for the AHLN." However, for others "advocacy" is too strongly associated with letter-writing campaigns and "in-your-face strategies." Most respondents promoted the use of more subtle forms of advocacy that can be done within government. The diverse perspectives within the AHLN on policy advocacy partly reflect the fact that "some members of the AHLN have advocacy as part of their mission, but most don't." For some respondents working in government, the sensitivities around a policy advocacy role stem from the perception of a conflict of interest since they are paid by government for the time they dedicate to the AHLN.

I think that [advocacy] needs to happen outside of the Network. I think if you get into real advocacy initiatives, the Network is not the place ... I think it needs to link [sic] and know what is going on—you know, pass information back and forth—but the Network is not in a good position to really do the advocacy. That needs to be something quite independent.

Many respondents also considered the political and social context in Alberta as a factor influencing the role of the AHLN in regard to policy advocacy. On the one hand, many made it clear that doing more health promotion is easier than it was five years

ago (though one respondent suggested that the province is "simply recouping some of the losses from 15 years ago"). On the other hand, there is relative consensus that the given context is generating real sensitivities and challenges regarding the reach of health promotion policies and those policies that address social and economic determinants of health:

It is pretty delicate—it is a pretty delicate issue ... because issues around poverty are so huge. And it is not just one ministry. In fact, most of that kind of stuff [is] outside the Ministry of Health, yet it is always Health that seems to be—I don't know if "implicated" is the right word—but [sic] "connected."

Discussions about a policy advocacy role for the AHLN led to the development of a screening tool used by an Advocacy Review Panel created in 2007 to help the Network decide which calls to action it would support. For example, AHLN documents produced in 2008 indicate that the Network will support the development of evidence-based position papers by AHLN experts, but not letter-writing campaigns. While the screening tool has brought a sense of resolution to the discussions on advocacy, it is "too little, too late" for those AHLN members who had disengaged themselves from the Network as a consequence.

Several respondents acknowledged that the challenges associated with defining the role of the AHLN is partly due to a lack of stable leadership. However, finding such leadership is a challenge, considering that most members have little time to dedicate to the AHLN and "do this work on the corner of [their] desk." A leadership transition affected the work of the AHLN during the period 2005 to 2006:

I think right now we've gone—I don't want to say backwards, but we've stalled a bit. And partly we stalled because we lost the Executive Director of AHLN for a long time and so there was a big gap ... [W]hen there is a gap in time in terms of leadership, things just don't move forward.

The financing of Network operations also affects how some respondents see the Network's role evolving with time. In 2006, when a contribution from the Alberta Cancer Board tripled the Network budget (from \$50,000 to \$150,000), most respondents welcomed the stronger secretarial support that the funds allowed. However, some also expressed the concern that funding from an organization that focused on a disease could hamper the push toward integrated action to address multiple diseases, with one respondent commenting, "To be totally frank, I think that money has not necessarily done the Network a favour ... we get away from integration just from that right there."

Defining the added value of the AHLN: measuring intangibles

Demonstrating the added value of the AHLN is another key challenge critical to its sustainability. Several respondents reflected on the past key outputs of the AHLN, often citing knowledge dissemination, the publication of the *AHLN Framework*¹¹ and the production of common and integrated messages about risk factors:

This [*AHLN Framework*¹¹] was a model that other provinces and territories followed, so I think this is a very good framework for [the Alberta] Healthy Living [Network] generally ... I think it made some real achievements in terms of education and awareness and bringing people together, and we did a lot of work around common messages and put common messages on our website so people have one point of reference ... I think it is something that we feel quite proud of—a lot of hard work.

A significant part of the Network's added value is difficult to measure. Respondents spoke of raising awareness, adopting a different "mindset," developing trust among Network members and the process of "mainstreaming health promotion":

One of the added values of the AHLN was to bring certain issues into the mainstream ... I think that the work the AHLN has done is creating an awareness of the social determinants of

health and their impact on all types of diseases, and that's probably the most valuable component that I have seen from the AHLN.

I feel that what very tangibly has changed is that there is a very strong level of trust that was not there before the AHLN.

Several respondents also spoke of the Network's consensus-based approach to making decisions, a factor that facilitates AHLN activities and promotes trust:

[O]ne thing that has been a real strength in our Network is [that] it is very consensus-based ... And I don't always agree with the decisions but I support them. I don't know better than anyone else, we are all there together, so if that's where the group wants to move, then that is fine, and I will continue to evaluate and assess whether it is meaningful and important for me or not.

Since all of these outcomes are difficult to assess, several of the respondents expressed concerns about the lack of sound process indicators to measure the success of the AHLN:

Another one of the really frustrating challenges: we don't have really good measures or [ways of showing] that we are making a difference in ... strengthening the system, strengthening the voice for health promotion. I see just a lot more levels of activity, strength of activity, ability to work together on shared issues and connect externally and learn from each other but I am stymied about how to get that on to something that looks like a graph.

The *Evaluation Framework*,[§] a companion document to the *AHLN Framework*,¹¹ was developed in response to early recognition of the need to evaluate the AHLN's activities. However, there was no consensus among the respondents about its usefulness and

applicability, some calling it "too big, too complex and too daunting." In summary, developing means to assess complex outcomes attributable to the AHLN remains a constant preoccupation.

Another challenge for measurement is that there is still limited evidence demonstrating or refuting the benefits of using an "integrated approach" for health promotion: "... maybe I am wrong, but we don't really know if integration is better ... You know, we know anecdotally that it is better, and that was one of the things that was our commitment to look at ..."

Sectoral and intersectoral collaboration

Intra- and intersectoral collaboration within government and the resultant increased awareness about the different roles in the field of CD prevention are perceived as very strong contributions to date: "By working together with other sectors—and I mean that's the bottom line—I guess I see less and less turf protection ... first off we need to understand what we are all doing in order to move the agenda."

However, improved collaboration is an achievement that is hard to quantify, and thus it remains one of the most significant challenges facing the Network. While several respondents felt that the Network is allowing members to better "connect the dots," concerns remain about the mix of sectors represented and how the demography of the Network (i.e. characteristics of its members) may affect the knowledge-to-action process:

I think it has been a real strength of our Network to have the provincial and federal government reps there; I think that has been ... key to moving some things forward and getting funding and being well connected. But to me personally, right now, there are kind of too many government sectors, so you can't really action a lot of things ... we need intersectoral action in government, but it needs to be something different from this.

Collaboration with the private sector is another key challenge for the Network. While partnership-building and intersectoral collaboration are the cornerstones of the Network, respondents agree that just inviting people from industry to the Network table will not result in partnerships with the private sector. What remains elusive is how to compel the private sector to join the Network and coordinate its activities with those of other Network members: "I really struggled: 'How do you engage industry in promoting health?' I think we have no choice but to work with industry, but how can we do it and do it right?"

There is an oil company that might be interested in participating. But to just sit at a Coordinating Committee—nobody's got time for that unless it's an integral part of their work ... most players and partners out there [in the private sector] have only an indirect connection. So we have to figure out what ... things that are of importance to them if we want to involve them?

Discussion

This study explored some of the key perceived benefits and challenges associated with activating and coordinating a network of 93 organizations to work collaboratively to prevent CDs and promote health in Alberta. The AHLN is still in its early years, but a deeper understanding of some of the aspects highlighted in this study may benefit similar intersectoral networks working in the field of CD prevention in particular and health promotion in general.

We believe that two major interrelated themes highlighted in this study of AHLN partnerships are highly relevant nationally and internationally: 1) the challenge, given the size of the organization, of managing contrasting expectations about the roles, actions and outputs or outcomes of the Network as a whole; and 2) the challenge of demonstrating the value of the AHLN given that such networks often lead to intangible outcomes related, for example, to interorganizational learning. These

§ The AHLN Evaluation Framework is available at: <http://www.ahln.ca/modules.php?name=Contentpub&pa=showpage&pid=4>

themes, in turn, may contribute to another key challenge highlighted in this study—how to keep such diverse members engaged in a network for the longer term.

With regard to the Network's purpose and actions, AHLN members held contrasting views about its priorities—actions at the community level versus influencing provincial government policy. While a true health promotion approach combines both perspectives,²⁴ respondents who worked for the provincial government were in favour of strengthening capacity at the community level but were less likely to want the Network to influence policy change. Although the creation of an Advocacy Review Panel in 2008 demonstrates a willingness on the part of AHLN members to tackle this point of debate, the fact remains that some respondents hold deeply rooted values and concepts about the role of public servants and the code of conduct that they are to follow (i.e. that they refrain from publicly expressing their policy preferences and play "behind the scenes"). A positive example of public-servant influence on policy development comes from the province of Quebec. There, civil servants helped tobacco-control activists improve their arguments in response to the claims of the tobacco industry and, in doing so, contributed to the adoption of new provincial tobacco-control measures.²⁵ However, there are examples of health promotion partnerships that very purposefully excluded government representatives because of the perception that their presence would prevent the use of effective advocacy mechanisms,²⁶ and there is an international push for the creation of health promotion foundations that are at arm's length from government in order to maintain accountability and transparency.²⁷ Partnerships and alliances involving both government representatives and representatives of civil-society organizations thus pose challenges if the end result is perceived to be government action.

Studies focusing on intersectoral partnerships commonly feature the problems of role definition and contrasting expectations among participants. A qualitative study of the Global Programme for Health Promotion Effectiveness highlights the

critical importance of inputs, processes and outputs on partnership functioning.²⁰ The study findings led to the development of the Bergen Model of Collaborative Functioning (BMcF), which includes traditional elements in terms of inputs (e.g. leadership), processes (formal versus informal structures) and innovates by presenting a partnership's mission as a type of input. It also proposes three different categories of outputs that can affect partnership functioning: 1) additive outputs, i.e. outputs that have not been affected by the interaction of the partnership; 2) synergistic outputs, i.e. outputs that could not have been achieved by one partner alone, with the partnership better able to be creative, holistic and realistic, attract new members and take action; and 3) antagonistic outputs, i.e. unwanted or disturbing outputs, or a lack of outputs, leading to the perception that the partnership is a waste of time and/or resources. Interestingly, the terms "outputs" and "outcomes" are used interchangeably in the BMCF, both referring to the expected and/or desired changes associated with the establishment of a partnership.

While the three categories of outputs presented in the BMCF are useful, they can be challenged by the empirical material presented in this paper. For example, it appears unrealistic to expect that all partners would share the same view about what is to be considered an additive, synergistic or antagonistic output. This is especially true if the concept of synergistic output is defined, as done by the authors, very broadly. Some members in a partnership may judge that some specific outputs are additive, i.e. that they would have happened even without the partnership, while others may argue that the partnership indirectly influenced the organization's processes and outputs through interorganizational learning (e.g. influencing the ability of the partner to think more holistically, etc.). With this variety of perspectives, there cannot be absolute definitions of the three types of outputs; the partners will have to collectively determine if the partnership is worth pursuing.

In the case of the AHLN, respondents varied considerably in their views on the

outputs of the Network. Some viewed the recruitment of new members as an accomplishment since it is a source of interorganizational learning, while others emphasized the potential impact of the AHLN on future programs and policies, with the view that the "learning organization" approach is never an end in itself but a route to improved performance. One of the outputs most desired by Network members was to increase capacity for CD prevention in the province of Alberta by building trust among members and increasing their capacity to work collaboratively.

But a key question remains: how can we best define the scope of influence of a network or partnership? Some networks limit their mission to knowledge exchange and interorganizational learning, while others would like to be associated with more "action-oriented" synergistic outcomes.²⁸ This study shows that members of the AHLN are divided. If knowledge and learning alone are accepted as a legitimate type of output or outcome, the Network can be seen to be more successful, but this may discourage the more action-oriented members. If the Network wishes to be action-oriented, it requires a long-term perspective; however, some members may disengage from the partnership because of the perceived lack of early successes if the action output is considered alone. In either case, there is a significant evaluation challenge.

Most respondents expressed concerns about the lack of indicators that reflect what they see as the main outcomes of the AHLN. These concerns correspond to what has been highlighted in recent studies in Canada about the investments from the CHHI, namely the need to develop indicators for capacity-building results.^{29, 30} The literature indicates that factors such as mutual trust, leadership and interpersonal relationships are essential for facilitating interorganizational relationships in health promotion. However, there are still major conceptual and methodological challenges to be met in quantitatively studying these complex concepts.^{18, 31, 32} From that perspective, qualitative studies such as this one offer unique opportunities for documenting the contributions of intersectoral

networks like the AHLN. Future monitoring and evaluation activities of the AHLN could benefit from using alternatives to logic model frameworks and indicator-based approaches. For example, Outcome Mapping (OM) focuses on changes in behaviour, relationships and activities in people, groups and organizations. OM puts people and learning at the focal point of attention and accepts unanticipated changes as potential for innovation.³³ The use of such an approach is also an essential first step for those interested in documenting the contributions of partnerships and networks to more traditional outcomes (e.g. better services, better programs, better policies).

Conclusions

This study examined the perceived benefits and challenges associated with the early implementation of an intersectoral network dedicated to CD prevention in Alberta, namely the AHLN. Our findings highlighted two key challenges likely to confront other intersectoral networks in the field of health promotion in general and CD prevention in particular: 1) reaching consensus on what actions and outcomes can be expected from large intersectoral networks; and 2) demonstrating the contributions and added value of such networks, short of an ultimate impact on disease or risk-factor rates. The early qualitative findings presented in this study suggest that, despite contrasting views about the scope and role of the Network, establishing the AHLN has led, from the perspective of the respondents, to an increased capacity to work intersectorally and collaboratively to strengthen CD prevention activities in Alberta. However, several of the respondents do not view this achievement as an end in itself and appeal to the Network to engage more in change-oriented activities. Managing contrasting expectations has had a significant impact on the functioning of the Network.

The emergence of intersectoral networks involved in health promotion in Canada in recent years, such as the AHLN, the British Columbia Healthy Living Alliance and the Chronic Disease Prevention Alliance of Canada, offers new opportunities to learn more about 1) how such networks operate;

2) what could be realistically expected of them and 3) how to evaluate their contributions.

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Appendix – Interview guide

During the semistructured interviews, we explored the following dimensions or themes: 1) the participants' (or interviewees') involvement with the AHLN; 2) the structure, description and evolution of the AHLN since its inception; 3) integration and partnerships; 4) the factors enabling or constraining the implementation of the AHLN; 5) the perceived impact of the AHLN; and 6) the future of the AHLN.

Note: A semistructured interview is flexible, allowing new questions to be brought up during the interview as a result of what the interviewee says. The questions below were asked of the interviewee, but several other questions, including probing questions, were improvised during the course of each interview. The interview guide also evolved during the course of the study.

Average duration: 90 minutes

1) Background information on the respondent

- Could you please tell me how long you have been involved with the AHLN?
- Could you please describe your main responsibilities and activities? How do you contribute to the work of the AHLN?

2) Structure, description and evolution of the AHLN

- Could you please describe the governance structures of the AHLN (executive committee, coordinating committee, etc.)?

- What changes have you witnessed/experienced within the AHLN since your initial involvement (in terms of vision, mission and organizational/governance structures)? How do you explain these changes?

- What forms of communication/interaction exist between the different members/organizations? How often do you meet? How are decisions made?

- Please describe the resource-allocation processes. What are the steps and challenges in negotiating financial support?

- The AHLN framework is focusing on five areas (healthy eating, active living, tobacco free, mental health and injury prevention). Could you please discuss how and why these priorities were selected?

- The AHLN framework has seven priority strategies: partnership development and community linkages; awareness and education; surveillance; best practices; research and evaluation; health disparities; and healthy public policies. Could you please discuss why these strategies were selected?

- Could you please tell me, from your perspective, what are the benefits and challenges of having a working group addressing each of the seven priority strategies of the AHLN?

3) Integration & partnerships

- What does the concept of integration mean to you? How would you characterize the AHLN in terms of integration? In what ways is your approach integrated?

- Could you please discuss the AHLN partnership model (membership, terms of reference, etc.)? What are the benefits and challenges?

^o Intersectoral collaboration (e.g. health-education-environment-media)

- Intrasectoral collaboration (e.g. public health and primary care interface)
- Community integration and partnerships
- International collaboration (e.g. WHO)
- What activities/programs focusing on the prevention and control of noncommunicable diseases are currently underway in Alberta outside of the AHLN? What institutions/organizations are involved? What forms of collaboration currently exist between these institutions/organizations?

4) Enabling and constraining factors

This is a transversal theme, and questions about the enabling/constraining factors will be asked when discussing "organizational structures" and especially "integration and partnerships." Additional questions (below) will be asked to validate and synthesize the information.

- From your perspective, what are the greatest strengths of the AHLN? What factors do you feel contributed the most to these strengths/successes?
- From your perspective, what are the greatest challenges/obstacles associated with the implementation of the AHLN? What factors do you feel contributed the most to limit/constrain the implementation of the AHLN?
- Could you please discuss again the factors that helped or limited community integration, intersectoral or international collaboration, or developing partnerships within the health sector?

5) The perceived impact of the AHLN

- How would you describe the impact of the AHLN so far?
 - Explore - visibility of the Chronic Disease agenda and challenges within government, communities and the health sector in general

- Explore - intergration and partnerships, (inter and intra sectoral collaboration)
- Explore - programs and policies
- How is the AHLN doing? What were the main findings of those evaluation studies?
- What impact do you feel the AHLN had on capacity-building in the following fields: social marketing; program evaluation, monitoring and surveillance; partnerships and collaboration; professional education?^{||}

6) Future of the AHLN

- How would you characterize the future of the AHLN?
- What characteristics of the AHLN do you consider unique and potentially useful for other jurisdictions?

References

1. World Health Organization. Preventing chronic diseases: a vital investment: WHO global report [Internet]. Geneva: World Health Organization; 2005 [cited September 20, 2008]. Available from: http://www.who.int/chp/chronic_disease_report/en/index.html
2. World Economic Forum, Working Towards Wellness Initiative. Working towards wellness: The business rationale [Internet]. Geneva: World Economic Forum; 2008. [cited September 20, 2008]. Available from: <http://www.pwc.com/extweb/pwcpublications.nsf/docid/6EE4249D9FCF6ADF85257415001A3EE8>
3. World Health Organization. Gaining health: The European strategy for the prevention and control of noncommunicable diseases. Copenhagen: World Health Organization; 2006.
4. World Health Organization; Government of Canada: WHO global forum IV on chronic disease prevention and control. Geneva: WHO/Health Canada; 2005.
5. Jacobs P, Klarenbach S, Ohinmaa A, Golmohammadi K, Demeter S, Schopflocher, D Chronic diseases in Alberta: cost of treatment and investment in prevention. Edmonton: Alberta Healthy Living Network; 2004. [cited September 20, 2008]. Available from: http://www.health-in-action.org/library/pdf/AHLN/whatsnew/Chronic_Diseases_in_AB.pdf.
6. Pan American Health Organization. Regional strategy and plan of action on an integrated approach to the prevention and control of chronic diseases including diet, physical activity, and health. Washington (DC): PAHO; 2007.
7. World Health Organization. Prevention and control of noncommunicable diseases: implementation of the global strategy. Geneva: World Health Organization; 2007.
8. World Health Organization. A strategy to prevent chronic disease in Europe: A focus on public health action: The CINDI vision. Copenhagen: World Health Organization; 2004.
9. Wolbeck Minke S, Smith C, Plotnikoff RC, Khalema E, Raine K. The evolution of integrated chronic disease prevention in Alberta, Canada. *Prev Chronic Dis*. 2006; 3(3):A102.
10. Jacobs P, Ohinmaa A, Golmohammadi K, Demeter S, Schopflocher D, Klarenbach S. Public investment in providing information for chronic disease prevention for adults in Alberta. *Can J Public Health*. 2006; 97(3):197-200.
11. Alberta Healthy Living Network. The Alberta Healthy Living Framework: An Integrated Approach. Calgary: Alberta Healthy Living Network; 2005. [cited October 17, 2008]. Available from: <http://www.ahln.ca/index.php>

|| areas of focus of the CINDI programme - the AHLN is part of the CINDI network

12. Alberta Healthy Living Network. Welcome to the AHLN [homepage on the Internet]. Calgary (AB): AHLN; 2009. [cited October 18, 2008]. Available from: <http://www.ahln.ca/index.php>
13. Scott WR: Organizations: rational, natural, and open systems. 5th ed. Upper Saddle River: Prentice Hall; 2002.
14. Huerta TR, Casebeer A, Vanderplaat M. Using networks to enhance health services delivery: perspectives, paradoxes and propositions. *Healthc Pap.* 2006;7(2):10-26.
15. O'Neill M, Lemieux V, Groleau G, Frodin F, Lamarche P: Coalition theory as a framework for understanding and implementing intersectoral health-related interventions. *Health Promot Int.* 1997;12(1):79-87.
16. Leurs MT, Mur-Veeman IM, van der Sar R, Schaalma HP, de Vries NK. Diagnosis of sustainable collaboration in health promotion—a case study. *BMC Public Health.* 2008;8:382.
17. Fear H, Barnett P. Holding fast: the experience of collaboration in a competitive environment. *Health Promot Int.* 2003;18(1):5-14.
18. Dunlop JM, Holosko MJ. The story behind the story of collaborative networks – relationships do matter! *J Health Soc Policy.* 2004;19(3):1-18.
19. Doncliff B. Collaboration is essential in health promotion. *Nurs N Z.* 2001;7(7):26-7.
20. Corbin JH, Mittelmark MB. Partnership lessons from the Global Programme for Health Promotion Effectiveness: a case study. *Health Promot Int.* 2008;23(4):365-71.
21. Moore S, Smith C, Simpson T, Minke SW. The influence of partnership centrality on organizational perceptions of support: a case study of the AHLN structure. *BMC Health Serv Res.* 2006;6:141.
22. Miles MB, Huberman AM. Qualitative data analysis: an expanded sourcebook. 2nd ed. Thousand Oaks, CA: Sage Publications; 1994.
23. Denzin NK, Lincoln YS. Handbook of qualitative research. Thousand Oaks, CA: Sage Publications; 2000.
24. O'Neil M, Pederson A, Dupéré S, Rootman I, editors. Health promotion in Canada: critical perspectives. 2nd ed. Ottawa, ON: Canadian Scholars' Press; 2007.
25. Breton E, Richard L, Gagnon F, Jacques M, Bergeron P. Fighting a tobacco-tax rollback: a political analysis of the 1994 cigarette contraband crisis in Canada. *J Public Health Policy.* 2006;27(1):77-99.
26. Potts-Datema W, Smith BJ, Taras H, Lewallen TC, Bogden JF, Murray S. Successful strategies and lessons learned from development of large-scale partnerships of national non-governmental organisations. *Promot Educ.* 2005; 12(3-4):131-137.
27. International Network of Health Promotion Foundations: Supporting the establishment of new Health Promotion Foundations: strategies for resource mobilization. Bangkok: International Foundation for Health Promotion; 2005 [cited March 6, 2009]. Available from: URL: [http://74.125.95.132/search?q=cache:dPDitVadS0wJ:www.hp-foundations.net/Strategies%2520for%2520resouce%2520mobilisation%2520\(Kickbusch\).pdf+Kickbusch+AND+HEALTH+PR+OMOTION+FOUNDATION&cd=6&hl=fr&ct=clnk&gl=ca](http://74.125.95.132/search?q=cache:dPDitVadS0wJ:www.hp-foundations.net/Strategies%2520for%2520resouce%2520mobilisation%2520(Kickbusch).pdf+Kickbusch+AND+HEALTH+PR+OMOTION+FOUNDATION&cd=6&hl=fr&ct=clnk&gl=ca)
28. McCall DS, Rootman I, Bayley D. International School Health Network: an informal network for advocacy and knowledge exchange. *Promot Educ.* 2005; 12(3-4):173-7.
29. Robinson K, Farmer T, Riley B, Elliott SJ, Eyles J; CHHDP Investigative Team, Strategic, and Research Advisory Groups. Realistic expectations: investing in organizational capacity building for chronic disease prevention. *Am J Health Promot.* 2007;21(5):430-8.
30. Robinson K, Elliott SJ, Driedger SM, Eyles J, O'Loughlin J, Riley B, Cameron R, Harvey D. CHHDP Strategic and Research Advisory Groups. Using linking systems to build capacity and enhance dissemination in heart health promotion: a Canadian multiple-case study. *Health Educ Res.* 2005;20(5):499-513.
31. Sepannen R, Blomqvist K, Sundqvist S. Measuring inter-organizational trust – a critical review of the empirical research in 1990-2003. *Ind Market Manage.* 2007;36(2):249-65.
32. Anderson D, Plotnikoff RC, Raine K, Barrett L. Development of measures of individual leadership for health promotion. *Int J Health Care Qual Assur Inc Leadersh Health Serv.* 2005;18(2-3):i-xii.
33. Earl S, Carden F, Smutylo T. Outcome Mapping: Building Learning and Reflection into Development Programs. Ottawa (ON): International Development Research Centre; 2001.

Navigating the health care system: perceptions of patients with chronic pain

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Abstract

A new framework is needed for patients with chronic pain and their primary care physicians that acknowledges the individual's experiences and provides evidence-informed education and better linkages to community-based resources. This study describes the experience of 19 chronic-pain sufferers who seek relief via the health care system. Their experiences were recorded through in-depth semistructured interviews and analyzed through qualitative methods. The participants reported early optimism, then disillusionment, and finally acceptance of living with chronic pain. Both individuals with chronic pain and their health care professionals need evidence-informed resources and information on best practices to assist them to manage pain. Empathetic communication between health care professionals and individuals with chronic pain is crucial because insensitive communication negatively affects the individual, reduces treatment compliance and increases health care utilization.

Key words: *chronic pain, empathetic communication, health care system, patients' perspectives, patient education, qualitative research, coming to terms*

Introduction

Pain is a complex phenomenon with physical, psychological, social and spiritual aspects. Chronic pain has a major effect on individuals and their families, on health care costs and on productivity. Individuals with chronic pain are frequent users of health care services,^{1,2} with most seeking to relieve their symptoms, primarily if the pain interferes with their day-to-day activities, or to determine if the pain indicates a serious pathology.^{3,4} Of the range of health care professionals, the primary care physician plays an important role in assisting patients to manage their pain and is a key source of information. Yet pain, particularly chronic pain, often remains unrelieved and the reasons why are not well understood.

Researchers have found that individuals' perceptions and management of their pain is influenced by their experiences with treatment regimes,⁵ their interactions with health care providers⁶⁻⁹ and their beliefs about the nature and causes of pain.^{4,10-13} The meanings of both pain¹⁴ and pain management regimes^{13,15,16} differ between patients and health care professionals. These differences in perceptions affect the patterns of help-seeking and adherence with treatment regimes.

People with pain often become socially isolated.¹⁷ They may be labelled as "malingers" and even "drug seekers" and seek recognition and acceptance from health care professionals as well as the broader society.¹⁸ As chronic pain can be frustrating and difficult to treat, patients

are often expected to accept their pain and to learn to manage it themselves.^{13,19-22} Chronic pain sufferers comment that health care providers vary in attitude, knowledge and understanding of the social and emotional impact of pain,^{8,11,23,24} expect adherence to the medical model of care⁸ and may not determine the patient's preferred management strategies.²³ At the health care systems level, pain management services are not coordinated²⁵ and evidence-based resources to assist both individuals and health care professionals are minimal. If health care professionals do not meet patient expectations, they either withdraw from care or "shop around" to find providers whose model of care coincides with their own.^{4,12} For chronic pain sufferers, interacting with the health care system can be complicated and stressful, and the outcome unsatisfactory. These circumstances promote the cycle of high use of health care services and unrelieved pain.

The purpose of this paper is to describe the perspectives of people with chronic pain as they seek relief via the health care system.

Methods

Description of the participants

Most participants were recruited through a mailing to a chronic pain support group, and two were recruited via snowball sampling.²⁶ Participants were eligible if they had back pain, neck pain or migraine headache, were between 40 and 65 years old and had experienced pain for a minimum of six months. Participants with

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back or neck pain or migraine headache were chosen because, according to Canadian population studies,^{27,28} these are the most common types of chronic pain. Pain here can have a marked effect on individuals: back pain can contribute to pain in the lower extremities and neck pain to pain in the upper extremities; migraine headache is an example of severe, episodic and unpredictable chronic pain. While chronic pain is defined as pain that exists for a minimum of three to six months, we chose six months as the minimum for this study so as to include those who would have had to manage their pain longer. As one ages, one is more likely to have chronic pain, and chronic pain sufferers, on average, have endured their pain for 10 years.^{27,28} The age range was set at 40 to 65 years to achieve homogeneity within a broad sample and to include those who may have had to become unemployed due to chronic pain and/or found it necessary to re-train or re-educate themselves for other careers.

Of the 19 individuals recruited, 15 had suffered chronic pain for more than ten years and four for less, with the duration of their pain ranging from 4 to 52 years; 12 were single, widowed or separated while seven were married; 13 were women. Participants represented various levels of education and types of employment. Two worked full-time, six worked part-time or were retired, and one was a full-time student; ten stated they were unable to work because of their chronic pain. All 19 participants had government-administered health care insurance that funded some of their health care needs including physician's visits; nine had third party insurance such as Worker's Compensation Boards, automobile insurance and supplementary health insurance.

Data collection and analysis

Ethics approval was obtained from the participating university and all participants provided informed consent.

Data were gathered with the help of a semistructured interview guide and included questions about how participants managed their pain, who helped them manage it and how they sought assistance for their

pain. Approximately half the interviews were done over the telephone and the remainder were face-to-face. Interviews ranged from 30 to 90 minutes. Participants were interviewed until data saturation was achieved, i.e. until no further information emerged from the interviews.²⁹ Six participants were re-interviewed to verify and expand upon the themes that were being found in the data.

Data analysis began with the first interviews. Data were analyzed by searching for themes. Preliminary codes that captured the participants' descriptions of their experiences were assigned.^{26,29} Second-level codes or categories were developed from these preliminary codes. Using constant comparative methods,³⁰ categories were examined for similarities and differences. Two researchers (A. D., K. G.) developed and verified the major conceptual categories. A third (J. M.), who was not involved in the data collection, assisted with the data analysis. An audit trail was established through a reflective journal and field notes.²⁹ Data diagrams were used to conceptualize the data as a whole.

Results

Coming to terms

The major category that evolved from the data, "Coming to terms," best described the participants' search for a cure or for better pain management. Attitudes changed from initial optimism to disillusionment and then to a level of acceptance of the realities of their pain and the limitations of the available health care. This time-consuming process often involved repeated interactions with different health care providers. Three subcategories evolved from the data: "Working with the system," "Changing perspectives" and "Becoming realistic."

Working with the system

Participants approached their primary care physician as a gatekeeper to the health care system, with the expectation that their pain would be relieved and the cause diagnosed. For most participants, this expectation was not met; thus began their struggle to seek a cause, find some relief or adjust to their pain.

Seeking a cause

The participants initially anticipated the cause of the pain would be determined. Given the nature of chronic pain, success could sometimes depend upon the persistence of the patient and/or physician though often a cause could not be found; in such cases, the participants often felt devastated as they believed this invalidated their pain. Other researchers have also found that a diagnosis legitimizes a sufferer's pain^{13,16,19,31} and reduces the perceived stigma associated with an invisible condition.³² It also establishes their credibility, not only to the physician, but also to family, employers, co-workers and friends.

I cannot believe that the MRI didn't show what's going on with me. I cannot believe with medicine today that something doesn't stand out like a sore thumb and say, "Oh goodness, no wonder the woman is like this."

Interacting with the primary care physician

Many participants indicated that having a supportive physician who provided guidance, sympathy and treatment options helped them manage their pain. A supportive relationship was characterized by the physician's willingness to listen to and believe them and to consider their perspective in treatment decisions. Even if the treatments did not relieve the pain, participants continued to visit their physicians if the relationship was supportive.

My physician [helps me manage my pain], I've been seeing him...[for some time] and [my pain] was difficult. ... I didn't know where the pain was coming from. Some days were worse. He tried different medications.

Many participants reported positive interactions with their physicians, but others found that their physicians were dismissive and hurried and did not provide information or solutions that relieved their pain. When they sought care for other health concerns, they considered that their physicians too quickly attributed these to their chronic pain.

When you go to the physician and say you have something else or you're not feeling well, they don't hear what you're saying because you've already talked to them about pain every visit for the last few years.

Whatever the relationship, participants depended upon their physicians to prescribe medications, provide information and refer them to medical specialists and other health care professionals. As this relationship was so vital, the participants developed various techniques to attract the physician's attention and maintain support. For instance, they learned not to overburden the physician with numerous complaints but only reported on "one pain" or on their major pain problem to stop him or her from "tuning out."

I got to learn that you didn't mention too much of your pain to the physician, you only mentioned a certain little bit that really concerned you.

Our findings support those of other researchers who argue that patients believe that they are primarily responsible for maintaining the relationship with their health care provider and use various strategies to preserve this important relationship.^{7,9}

Chronic pain can also limit patients' access to diagnostic procedures as well as referrals to other health care professionals and medical specialists, particularly when third party insurers are involved. Certain diagnoses, such as failed surgeries or fibromyalgia, or involvement in litigation labelled patients as "risky," and some physicians were hesitant to take them under their care.

My [primary care physician] was moving ... and I was trying to find a new GP and it's like finding a needle in a haystack. Nobody wants this. I know it's not me personally but there's too many [health care problems] going on. I'm a complex patient.

Changing perspectives

When their pain was not relieved and/or a cause or diagnosis not established, many

participants became disenchanted with their health care providers and the health care system; they began to view their pain and their health care differently and search for alternatives. This change in perspective was also influenced by conflicting messages about treatment and by their experiences and beliefs about the effectiveness of medications, causing them to feel anxious about finding help.

Conflicting messages about treatment

Participants reported receiving confusing or conflicting information from different physicians and health care providers. For some, this affected their willingness to seek further treatment. Even having a diagnosis did not always explain the pain or give direction for satisfactory treatment, leaving participants sceptical and concerned about where to get assistance.

[S]o they said there was no correlation, it didn't fit ... I thought, "Oh well, they must be right, of course." ... The physicians were gods to me at that point, and I went for MRIs, I went for all kinds of things, and the more physicians you see, the more opinions you get ... So you're left totally confused as to what direction you should take or what is really going on with you. I sort of opted to just do it myself, go home and do the natural thing and let my body heal, but it didn't, it never did.

I'm doing what seems to work but I don't know if it's the best thing. Nobody has ever discussed that with me. I've been given prescriptions for painkillers and told to take them as needed, and some physicians seem to [sic]—like the rehab physician—think you should take as little as possible.

Concerns about medications

While intending to provide relief, medications were sometimes a major source of concern and even conflict between the participants and their primary care physicians, particularly if there were troublesome side effects, or if the participant's knowledge, beliefs or experiences were at variance with those of the physician.

I dropped the anti-seizure medication ... because I'd broken out really bad [sic] on my hand—severe blistering. My physician kept trying to convince me it was dermatitis ... After 3 months of trying cortisone, steroids ... I couldn't wash my dishes under warm water, I would go through the roof. I decided to personally try to reduce my dose to 300 mg a day.... My skin improved.

Many participants did not understand how to manage their medications or the role they played in their treatment. Some reported that pain medications worked for a while and then stopped; several reported that they became "allergic" to medications or that they were afraid of becoming addicted. Antidepressants were a common source of concern and best represent physicians' and patients' differing perspectives. Many participants were ambivalent about the helpfulness of antidepressants and either restricted their use or wanted alternative methods for dealing with their mood and their pain.

I refused to go on 150 mg of [antidepressant]. It was like a tug of war. He thought I was sabotaging myself and didn't understand why I was spending so much money to go to physiotherapists ... I don't care what they say about it not being addictive—it's a bunch of bull.

Side effects were not the only concern regarding prescriptive medications. Some of those participants who were prescribed opioids believed that their physician labelled them as "drug-seeking" and they felt mistrusted. Additionally, opioids can contribute to feelings of dependency, inequity and vulnerability among chronic pain sufferers.

I just couldn't do that revolving door right now. Going for pain medication and trying to save them, drag them out as long as I possibly could, so I had something for pain because it's humiliating going back for more. When you take your last, it's horrible.... It's

so humiliating more than anything. The idea that the physician doesn't trust you and believe you.

While patients are reluctant to take opioids and other pain-relieving medications,^{10,23,35} there has been little research regarding reservations about taking antidepressants for pain.³⁴ Piguet found that patients did not associate antidepressants with pain relief and felt the physician did not believe that they were in pain.³⁴ Our participants commented that medications and their side effects were the "double-edged sword" of pain treatment and a major factor in their change in perspective on the health care system. Their comments also illustrate that their interactions with prescribers influence their feelings about themselves as pain sufferers; likewise, prescribers' pain management practices influence their patients' beliefs about medications.¹⁰

Searching for alternatives

The participants became disillusioned with conventional health care when they felt invalidated, when there were unresolved differences about treatment decisions and when there was a lack of shared decision making. To address their pain and dissatisfaction, they tried other options: changing primary care physicians, seeing other health care professionals or seeking further information. Complementary and Alternative Medicine (CAM) was an option and an adjunct to prescription medications for many, particularly if patients were afraid of addiction or otherwise concerned about conventional medications. Some participants were enthusiastic about CAM practitioners because they devoted more time to them and managed their health in a holistic manner.

Oh, and I saw a naturopath one time. It was like nothing I had ever experienced. He asked me everything about mental, physical, spiritual health. It was a two-hour appointment ... I saw him occasionally when I was fed up with the medical system, and he usually came through with something helpful.

As with conventional medicine, CAM did not work for everyone, and some approaches were expensive. Some participants reported that CAM medications seemed to work for only a while and that some had side effects.

In my specific case, I tried all kinds of alternative treatment but a lot of them didn't work because it's very individual.

Patients' disillusionment with CAM for pain management is not widely reported in the literature.¹⁶ However, more pain sufferers are turning to CAM, and there are varying reports of efficacy when CAM is used alone or in conjunction with conventional therapies.³⁶

Becoming realistic

Often many interventions or combinations of interventions, such as exercise, pain-relieving medications or CAM, appeared to work, but only temporarily. The participants, weary of having their hopes repeatedly raised and dashed with only short-term relief, became reluctant to seek care. This phase involved acknowledging the system's limitations, accepting the reality of the pain and seeking information to assist them to manage.

Acknowledging the system's limitations

Participants described a transition when they were able to move from searching for a cure and being dependent on the medical system to the realization that the pain was ongoing. They did not expect a quick cure, but they kept their options open while functioning within their limitations.

I went through the gamut of homeopaths, naturopaths, pain clinics ... it all works for a short time. The hardest part of the situation is to accept that my life is full of pain, and I have to make the best of it and go on. I wouldn't say I'm not willing to try new things. I'm more sceptical of it.

For some participants, becoming realistic meant they learned to find a balance between interventions. During this stage, many began to reduce their use of prescription medications and incorporate their

knowledge of other treatment methods into a regime that helped them.

In the middle of the night ... I will use Reiki. Then ... I will use hypnosis to go back to sleep. I did the pain course. I'm hoping it will help me.

Accepting the reality of the pain

Current pain practice generally encourages acceptance of chronic pain, as opposed to an ongoing search for a cure. However, health care professionals should be cautious when discussing acceptance as a goal for patients living with a chronic condition.²² The numerous definitions of acceptance^{37,38} indicate that terms and their meanings need to be carefully communicated between patient and physician.

Most participants did not respond positively when health care professionals told them that they must accept the situation and "live with the pain." Such comments were viewed as an excuse for not determining the cause and placing the onus on the patient to accept the situation. Acceptance was equated with physicians not trying to find a solution.

You can't just accept your pain because if you just accept it, you won't have a life. You have to find ways of easing the pain or you won't be able to function. But people accept it because they're frustrated with medical advice or lack of it.

Conversely, others reported a different view of acceptance and indicated that accepting chronic pain meant that their search and hope for relief had ended. For these individuals, becoming realistic meant learning to endure the pain. Acceptance was helpful in dealing with their situation.

I've searched for 20 years and then gave up searching ... I have tried everything—relaxation, biofeedback, magnet therapy. I'm at the point where it takes too much [sic] energy than I've got and I don't use my energy trying anymore.

Seeking information

People with chronic pain want clear explanations about the diagnosis and treatment, and supportive reassurance and advice about pain management.^{5,16,19,39,40} Many participants described obtaining information through formal and informal sources. Support groups provided access to experts and allowed them to share ideas and experiences with their peers. This type of support empowered them to make more informed choices and was an important adjunct to the care offered by their physicians.

My support group meetings are important; when I went to the first meeting, they had a pharmacist there and suddenly all my stomach problems were resolved because I discovered [my stomach problem was due to] my pain medication. [I get] information from various support groups ... I've met people through these and learned a lot.

Participants who used group support and educated themselves about pain management generally spoke in more positive terms about their situations and interactions with health care providers. However, not all participants were members of these organizations. Some stated they did not find these "pity parties" helpful and chose to manage pain on their own.

Discussion

Coming to terms with the pain was a process of working with the system, changing perspectives and adjusting to the reality of pain. This complex process involved a series of difficult personal transitions. As the participants learned that their chronic pain was not going away, they also learned that their physicians were not able to provide all the answers and solutions, and that available treatments had side effects and limitations. However, a trusting and supportive relationship with a physician who believed their complaints and helped them to become less dependent on the health care system and more reliant upon themselves was important; non-supportive encounters, on the other hand, could lead to a personal disconnection with the health

care system, or a withdrawal. Because of their numerous and, at times, prolonged encounters with the health care system, participants who were involved with third party insurers were particularly prone to withdrawing and becoming discouraged about finding relief. This disconnection has many ramifications, the most important being that pain sufferers do not obtain the treatment that they require for other comorbid conditions. Their perceived need to be responsible for managing their interaction with their health care providers increases the many troublesome burdens associated with chronic pain. Patients need a combined approach to pain management—and the support to try these various approaches—that incorporates different strategies that can work alone or in combination with medications.

Conclusion

Even if the cause of the pain is not diagnosed, patients need confirmation that their chronic pain is "real" and want to feel empowered through access to consistent and reliable information on best practices. This suggests that there is a lack of accessible evidence-based resources to help patients and health care professionals, that existing resources are underutilized and that communication between health care providers and patients needs to improve.

The emphasis on "acceptance" as the patient's responsibility can create an additional barrier between patients and physicians. An important finding was the degree to which the perception of contradictory diagnosis and treatment advice played in building scepticism and dissatisfaction, which resulted in high utilization of or withdrawal from the health care provider and the health care system.

Practice implications

Both health care professionals and patients need a better framework to address chronic pain. The study participants were seeking better information about types of medications, non-pharmaceutical options and CAM. Further research on the efficacy of CAM and conventional therapies for pain management could reduce the economic burden of this vulnerable population.

The participants frequently commented that they were not heard and that they were not being provided with consistent information about best practices; health care professionals should be aware of the differing expectations between patients and practitioners and provide support, focusing on how they can best assist the person to deal with the realities and ambiguities of chronic pain. Further research is needed on how to improve communication between health professionals and patients. At the health care systems level, services need to be coordinated to provide improved access.

With the prevalence of chronic pain in the population and its socio-economic burden, there is an urgent need to reduce the gap between current research and health care practice and to provide evidence-based resources to chronic pain sufferers and their families. There is a need to synthesize and mobilize our current knowledge base to support health care professional training and consumer education.

Limitations to the study

Most of the participants were recruited from the member database of a chronic pain education and support organization; they represent those who are willing and able to join these associations. The participants were relatively well educated and may be less vulnerable and have more options than pain sufferers from a lower socio-economic position.

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References

1. Badley EM, Kasman NM. The impact of arthritis on Canadian women. *BMC Womens Health*. 2004;4 Suppl 1:S18.
2. Weir R, Browne G, Tunks E, Gafni A, Roberts J. Gender differences in psychosocial adjustment to chronic pain expenditures for health care services used. *Clin J Pain*. 1996; 12(4):277-90.
3. McPhillips-Tangum CA, Cherkin DC, Rhodes LA, Marckham C. Reasons for repeated medical visits among patients with chronic back pain. *J Gen Intern Med*. 1998;13(5):289-95.
4. Ross MM, Carswell A, Hing M, Hollingworth G, Dalziel WB. Seniors' decision making about pain management. *J Adv Nurs*. 2001;35(3): 442-51.
5. Blake S, Ruel B, Seamark C, Seamark D. Experiences of patients requiring strong opioid drugs for chronic non-cancer pain: a patient-initiated study. *Br J Gen Pract*. 2007; 57(535):101-8.
6. Haugli L, Strand E, Finset A. How do patients with rheumatic disease experience their relationship with their doctors? A qualitative study of experiences of stress and support in the doctor-patient relationship. *Patient Educ Couns*. 2004;52(2):169-74.
7. Daykin AR, Richardson B. Physiotherapists' pain beliefs and their influence on the management of patients with chronic low back pain. *Spine*. 2004;29(7):783-95.
8. Walker J, Holloway I, Sofaer B. In the system: the lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *Pain*. 1999;80(3):621-8.
9. Werner A, Malterud K. It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors. *Soc Sci Med*. 2003;57:1409-19.
10. Dawson R, Sellers DE, Spross JA, Jablonski ES, Hoyer DR, Solomon MZ. Do patients' beliefs act as barriers to effective pain management behaviors and outcomes in patients with cancer-related or noncancer-related pain? *Oncol Nurs Forum*. 2005;32(2):363-74.
11. Liddle SD, Baxter GD, Gracey JH. Chronic low back pain: patients' experiences, opinions and expectations of clinical management. *Disabil Rehabil*. 2007;29(24):1899-909.
12. Parsons S, Harding G, Breen A, Foster N, Pincus T, Vogel S, Underwood M. The influence of patients' and primary care practitioners' beliefs and expectations about chronic musculoskeletal pain on the process of care: a systematic review of qualitative studies. *Clin J Pain*. 2007;23(1):91-8.
13. Verbeek J, Sengers MJ, Riemens L, Haafkens J. Patient expectations of treatment for back pain: a systematic review of qualitative and quantitative studies. *Spine*. 2004; 29(20):2309-18.
14. McIntosh A, Shaw CF. Barriers to patient information provision in primary care: patients' and general practitioners' experiences and expectations of information for low back pain. *Health Expect*. 2003;6(1):19-29.
15. Bullington J, Nordemar R, Nordemar K, Sjöström-Flanagan C. Meaning out of chaos: a way to understand chronic pain. *Scand J Caring Sci*. 2003;17(4):325-31.
16. Rhodes LA, McPhillips-Tangum CA, Markham C, Klenk R. The power of the visible: the meaning of diagnostic tests in chronic back pain. *Soc Sci Med*. 1999;48(9):1189-203.
17. Sofaer-Bennett B, Walker J, Moore A, Lambert J, Thorp T, O'Dwyer J. The social consequences for older people of neuropathic pain: a qualitative study. *Pain Med*. 2007;8(3):263-70.
18. Henriksson CM. Living with continuous muscular pain: patient perspectives. Part 1: Encounters and consequences. *Scand J Caring Sci*. 1995;9(2):67-76.
19. Lillrank A. Back pain and the resolution of diagnostic uncertainty in illness narratives. *Soc Sci Med*. 2003;57(6):1045-54.
20. Steihaug S, Ahlsen B, Malterud K. "I am allowed to be myself": women with chronic muscular pain being recognized. *Scand J Public Health*. 2002;30(4):281-7.
21. Thomas SP. A phenomenologic study of chronic pain. *West J Nurs Res*. 2000; 22(6):683-705.
22. Telford K, Kralik D, Koch T. Acceptance and denial: implications for people adapting to chronic illness: literature review. *J Adv Nurs*. 2006;55(4):457-64.
23. Lansbury G. Chronic pain management: a qualitative study of elderly people's preferred coping strategies and barriers to management. *Disabil Rehabil*. 2000;22 (1-2):2-14.
24. Sofaer B, Moore AP, Holloway I, Lambert J, Thorp TA, O'Dwyer J. Chronic pain as perceived by older people: a qualitative study. *Age Ageing*. 2005;34(5):462-6.
25. Maddison P, Jones J, Breslin A, Barton C, Fleur J, Lewis R, McSweeney L, Norgain C, Smith S, Thomas C, Tillson C. Improved access and targeting of musculoskeletal services in northwest Wales: targeted early access to musculoskeletal services (Teams) programme. *BMJ*. 2004;329(7478):1325-7.
26. Morse JM. Emerging from the data: The cognitive process of analysis in qualitative data. In: Morse JM. ed. *Critical issues in qualitative research methods*. Thousand Oaks: Sage; 1994.
27. Birse TM, Lander J. Prevalence of chronic pain. *Can J Public Health*. 1998;89(2):129-31.
28. Moulin DE, Clark AJ, Speechley M, Morley-Forster PK. Chronic pain in Canada: prevalence, treatment, impact and the role of opioid analgesia. *Pain Res Manag*. 2002;7(4):179-84.
29. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Beverly Hills: Sage; 1985.
30. Boeije H. A purposeful approach to the constant comparative method in analysis of qualitative interviews. *Qual Quant*. 2002; 36(4) 391-409.

31. Clarke KA, Iphofen R. Believing the patient with chronic pain: a review of the literature. *Br J Nurs*. 2005;14(9):490-3.
32. Holloway I, Sofaer-Bennett B, Walker J. The stigmatisation of people with chronic back pain. *Disabil Rehabil*. 2007;29(18):1456-64.
33. Banbury P, Feenan K, Allcock N. Experiences of analgesic use in patients with low back pain. *Brit J Nurs*. 2008;17(19):1215-18.
34. Piguët V, Cedraschi C, Dumont P, Desmeules J, Allaz AF, Dayer P. Patients' representations of antidepressants: a clue to nonadherence? *Clin J Pain*. 2007;23(8):669-75.
35. Artus M, Croft P, Lewis M. The use of CAM and conventional treatments among primary care consultants with chronic musculoskeletal pain. *BMC Fam Pract*. 2007;8:26. Available from: <http://www.biomedcentral.com/1471-2296/8/26>.
36. Fleming S, Rabago DP, Mundt MP, Fleming MF. CAM therapies among primary care patients using opioid therapy for chronic pain. *BMC Complement Altern Med*. 2007;7:15. Available from: <http://www.biomedcentral.com/1472-6882/7/15>.
37. Risdon A, Eccleston C, Crombez G, McCracken L. How can we learn to live with pain? A Q-methodological analysis of the diverse understandings of acceptance of chronic pain. *Soc Sci Med*. 2003;56(2):375-86.
38. McCracken LM, Evon D, Karapas ET. Satisfaction with treatment for chronic pain in a specialty services: preliminary prospective results. *Eur J Pain*. 2002;6(5):387-93.
39. Kenny DT. Constructions of chronic pain in doctor-patient relationships: bridging the communication chasm. *Patient Educ Couns*. 2004;52(3):297-305.
40. McHugh G, Thoms G. Living with chronic pain; the patient's perspective. *Nurs Stand*. 2001;15(52):33-7.

School-based tobacco-control programming and student smoking behaviour

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Abstract

The study examined the association of a school-based tobacco-control program with students' smoking behaviour over time using three cross-sectional, provincial census datasets (grade 10 students in 1999, grade 11 students in 2000, grade 12 students in 2001). Data were collected from all secondary schools in Prince Edward Island (Canada) using the Tobacco module of the School Health Action, Planning and Evaluation System (SHAPES). The proportion of regular smokers increased from grade 10 (22.3%) to grade 12 (27.8%, $\chi^2 = 10.35$, $df = 1$, $p < 0.001$). Being exposed to different school-based tobacco programs and policies in grades 10 and 11 was not associated with the smoking behaviour of grade 12 students. The strongest predictors of smoking behaviour were having friends or close family members who smoke. This preliminary evidence suggests that programs and policies associated with banning smoking and enforcing smoking restrictions at school may be insufficient unless they also address the influence of smoking peers and family members and link to comprehensive programming within the broader context of other community and policy level interventions.

Key words: policy, schools, tobacco control, social and environmental influences

Introduction

Early initiation of tobacco use is associated with a longer time spent smoking, thus increasing the risk of many tobacco-related diseases.^{1,2} Despite the overwhelming evidence of the harmful effects of smoking,³ youth smoking rates remain high in Canada.⁴ Most smokers (about 80 to 90%) start smoking while at school⁵ and rates of smoking increase from youth to young adulthood.^{6,7} According to the 2006 Canadian Tobacco Use Monitoring Survey, nationwide 15% of 15- to 19-year-olds and 27.3% of 20- to 24-year-olds were current smokers, while in the province of Prince Edward Island (PEI), 14% of 15- to 19-year-olds and 31% of 20- to 24-year-olds were current smokers⁷. Moreover, the increasing use of tobacco by youth in PEI schools

was reported to range from a low of 3% of grade seven students to a high of 24% of grade 12 students.⁸ This increase in the smoking behaviour of youth as they transition through high school represents a real health concern.

A strong body of literature supports the influence of family (parents and siblings), "popular kids", close friends and the school environment on youth smoking behaviour.⁹⁻¹⁵ Previous studies have shown that, while school-based interventions may increase knowledge about the effects on health of tobacco,¹⁶ they have had limited impact on tobacco-control efforts with youth.¹⁶⁻¹⁹ School-based prevention programs can be improved when they are combined with intensive

community-based interventions, and home supports such as parental supervision.^{12,13,20,21} School-level tobacco-control policies^{1,12,22,23} may contribute to youths' decisions not to smoke.¹⁴ Students spend about 25 hours each week in school during which time they could be continually exposed to programs, policies and peer group activities to reduce or prevent tobacco use. Understanding how these different social and school influences may either support or inhibit tobacco use may contribute to a better understanding of the roles of schools in tobacco control.

This study was a part of a comprehensive tobacco preventive initiative called the Prince Edward Island Tobacco Reduction Alliance (PETRA) that was officially launched in the fall of 1998. Between 1999 and 2001, PEI introduced a province-wide initiative to implement both school-based policies banning smoking on school grounds and school-based smoking prevention programming phased in over a three-year period in all schools. During this time, PETRA also continued to work towards enforcement of banning smoking in public places such as restaurants, bars, shopping centres and work places and enhancing tobacco control initiatives across the province.

Our previous results, using data from the PETRA initiative, showed significant differences in the influences of policy and programs on the smoking behaviour of grade 10 and grade 12 students.^{24,25} For grade 10 students, attending a school

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with both smoking-prevention policies and programs was not associated with a decreased risk of occasional smoking; however, the grade when youth enrolled in high school, the smoking behaviour of senior students and close friends, and clear rules about smoking at school were associated with the effect of school-based tobacco programming. For grade 12 students, attending schools with smoking-prevention programming was associated with a decreased risk of occasional smoking (Odds ratio [OR] = 0.42, 95% confidence interval [CI]: 0.18, 0.95) and school-based policies banning smoking on school property were associated with a small increased risk of occasional smoking (OR = 1.06, 95% CI: 0.67, 1.68).

Given the findings from those studies, we were interested in understanding the experience of one group of high school students who might have witnessed the implementation of the tobacco policy and programs as they moved from grade 10 (at 15 to 16 years old) to grade 11 (at 16 to 17 years old) when four schools were introduced to the policy and six schools were introduced to programs, and then to grade 12 (at 17 to 19 years old) when all 10 schools had both the policy and the programs. Understanding how these different social and school influences may either support or inhibit tobacco use would provide valuable insight for future prevention programs within PEI and other jurisdictions. The purpose of this paper was to determine the factors that most influence whether or not a school-based tobacco-control program influenced the smoking behaviour of students during their transition through high school (grades 10 to 12).

Methods

Sampling procedure

We collected repeated cross-sectional smoking behaviour data from a census sample of all 10 English-speaking secondary schools* in PEI over three years (1999, 2000, 2001) using the tobacco module of the School Health Action, Planning and Evaluation

System (SHAPES).²⁶ Overall, there were 13 131 observations over three waves of data collection ($n = 4114$ in 1999, $n = 4427$ in 2000, $n = 4590$ in 2001). For this paper, we reported on a group of students who were eligible to be followed over all three waves of data collection, grade 10 students in 1999 ($n = 1537$), grade 11 students in 2000 ($n = 1514$) and grade 12 students in 2001 ($n = 1429$). Without having longitudinally linked data, these observations are our most accurate representation of the students who may have participated in all three years of the study.

In Year 1 (1999), none of the schools had policies banning smoking on school property or were participating in provincially directed school-based smoking prevention programs; in Year 2 (2000), four of the schools had introduced a policy banning smoking on school property and the remaining six schools had implemented provincially directed school-based smoking prevention programs (Students Working in Tobacco Can Help [SWITCH] and Kick the Nic^{24,25}); in Year 3 (2001), all 10 schools had introduced a policy banning smoking on school property and implemented the provincially directed school-based smoking prevention programs (SWITCH and Kick the Nic).

Measures

Demographic variables included age, grade and gender. We identified three smoking behaviours (smoking status): regular smoker (smokes every week), occasional smoker (smokes less often than weekly) and current non-smoker (never smoked or tried once but quit). Student characteristics included misperceptions about smoking behaviour of other youth their age, i.e. inaccurate estimation of the number of fellow students who actually smoke. School and environment characteristics included seeing fellow students smoking near the school, seeing teachers or staff smoking near the school, clear smoking policy rules existing in the school, students getting in trouble if they break the smoking rules, students smoking where they are not allowed in the school, and students

being asked their age when buying cigarettes. Social influences included the number of smokers in the students' homes and the number of their close friends who smoke.

Questionnaire implementation

Data collection and research protocol procedures are fully described elsewhere.^{24,25} Briefly, teachers implemented the tobacco-use questionnaires during class time using an exam-type protocol.^{19,24} In accordance with ethical requirements, all data on the surveys were collected anonymously so that individual student smoking behaviour could not be tracked over time. The University of Prince Edward Island Research Ethics Board and appropriate school board ethics' committees approved all procedures, including passive consent.

Analysis

We examined changes in the prevalence of smoking and related characteristics over time with that group of students who may have participated in all three years of this study (grade 10 in 1999, grade 11 in 2000 and grade 12 in 2001) using descriptive statistics and chi-square analyses. In order to understand the characteristics that are associated with smoking behaviour by the end of high school, we conducted three logistic regression models using the grade 12 (2001) sample to differentiate current non-smokers from occasional smokers, occasional smokers from regular smokers, and current non-smokers from regular smokers. These analyses were also done separately by gender. SPSS 15.0 was used to conduct the analyses.²⁷

Results

Table 1 shows the descriptive characteristics of student smoking behaviours. The majority of the students ranged in age from 15 to 19 years, were located predominantly in rural schools (70%), with slightly more females (about 52%) than males. There was a significant increase in the proportion of regular smokers from 1999 to 2001 ($\chi^2 = 10.35$, $df = 1$, $p < 0.001$) and a significant decrease in current non-smokers ($\chi^2 = 7.93$, $df = 1$, $p < 0.01$).

* The French school district was not included because confidentiality could not be guaranteed when reporting the data due to the small sample size of students.

School and environment characteristics and smoking behaviour

Between Year 1 (1999) and Year 3 (2001), there were significant decreases in reports of seeing students smoking near the school property ($\chi^2 = 42.57$, $df = 1$, $p < 0.001$) and teachers or staff smoking near the school property ($\chi^2 = 35.44$, $df = 1$, $p < 0.001$); students overestimating the percentage of students their age who smoke ($\chi^2 = 80.25$, $df = 1$, $p < 0.001$); and students being exposed to smoking in the home ($\chi^2 = 8.16$, $df = 1$, $p < 0.001$). Moreover, school policies and enforcement of those policies also improved during the three years of the study, with a greater percentage of students reporting that clear smoking rules were in place in their school ($\chi^2 = 49.68$, $df = 1$, $p < 0.001$) and that students who break the rules get in trouble ($\chi^2 = 18.95$, $df = 1$, $p < 0.001$).

School and environmental factors associated with current non-smoking versus occasional smoking (grade 12)

Table 2 shows the characteristics associated with differentiating current non-smokers from occasional smokers. In the full model, the only significant characteristic associated with an increased risk of being an occasional smoker was having one or more close friends who smoke. The odds of being an occasional smoker increased for students with one or more close friends who smoke (OR = 2.57; 95% CI = 1.86, 3.56). The gender specific models showed that having friends who smoke increased the likelihood of being an occasional smoker among female students (OR = 2.99; 95% CI = 1.94, 4.61) more than among male students (OR = 2.11; 95% CI = 1.29, 3.46). Female students who saw other students smoking where they were not allowed were more likely to be occasional smokers than male students (OR = 1.58; 95% CI = 1.02, 2.47). Moreover, female students were more likely than male students to be occasional smokers (OR = 1.38; 95% CI = 1.00, 1.88).

School and environmental factors associated with occasional smoking versus regular smoking (grade 12)

Table 3 shows the characteristics associated with differentiating occasional smokers from regular smokers. In the full model,

two characteristics were associated with an increased likelihood of being a regular smoker: having one or more family members in the home who smoked (OR = 2.58; 95% CI = 1.76, 3.79) and having one or more close friends who smoke (OR = 14.47; 95% CI = 7.17, 29.20). When the models were run separately by gender, there was a difference in the size of the effect for close friends' smoking. For male students who had close friends who smoke, the odds of being a regular smoker were 17 times that of those who had no close friends who smoke (OR = 17.69; 95% CI = 6.43, 48.67). Similarly, female students who had one or more friends who smoke were 12 times more likely to be regular smokers compared to those with no close friends who smoke (OR = 12.06; 95% CI = 4.52, 32.22). Both male and female students with one or more smokers in the home were more likely to be regular smokers compared to students with no smokers in the home (female students, OR = 2.48; 95% CI = 1.49, 4.14; male students, OR = 2.63; 95% CI = 1.45, 4.76).

School and environmental factors associated with current non-smoking versus regular smoking (grade 12)

Table 4 shows the characteristics that differentiated current non-smokers from regular smokers. In the full model, three characteristics were significantly associated with being a regular smoker compared to a non-smoker: students who have one or more close friends who smoke compared to those with no close friends who smoke (OR = 37.46; 95% CI = 19.39, 72.36); who have one or more smokers in the home compared to those with no smokers in the home (OR = 2.35; 95% CI = 1.67, 3.30); and who see teachers and staff smoking on or near school property compared to those who did not report seeing teachers smoking near the school property (OR = 1.78; 95% CI = 1.13, 2.80).

Separate models for gender differences showed that the strongest influence on regular smoking behaviour for both male and female students was having one or more close friends who smoke. Female students with one or more close friends who smoke were over forty times more

likely to be regular smokers than those with no close friends who smoke (OR = 41.16; 95% CI = 16.10, 105.20). Similarly, male students with one or more close friends who smoke were over thirty-six times more likely to be regular smokers than those with no close friends who smoke (OR = 36.04; 95% CI = 14.11, 92.05). Having one or more smokers in the home was associated with being a regular smoker for both female students (OR = 2.58; 95% CI = 1.56, 4.25) and male students (OR = 2.17; 95% CI = 1.33, 3.51). Female students who estimated that over 30% of their peers smoke were twice as likely to be regular smokers (OR = 2.39; 95% CI = 1.36, 4.21). Similarly, female students who reported seeing students smoke where they are not allowed were more likely to be regular smokers than those who didn't (OR = 2.32; 95% CI = 1.37, 3.93). Seeing teachers and staff smoking near the school was associated with an increased likelihood of regular smoking for male students (OR = 2.43; 95% CI = 1.35, 4.38).

Discussion

To our surprise, the prevalence of regular smoking among this group of secondary school students in PEI increased as they moved from grade 10 through 12. The tobacco-control initiatives implemented in PEI over the three years of data collection did not cause smoking rates to plateau—let alone decline—as youth in the province transition through adolescence. The comprehensive programming may not have been sufficiently intense or frequent to have had an effect.

However, although it may appear that this prevalence of regular smoking among this age of students was a result of a failure in the programming, it may also be a function of the natural timing of youth smoking behaviour, with rates of smoking onset peaking at this age. In fact, the literature consistently demonstrates that the smoking rates of senior high school students (i.e. grade 12) are usually higher than that of their younger colleagues.^{19,28} There was no systematic data collection or evaluation completed around other community level interventions to determine what might have contributed to youth tobacco control. Our

TABLE 1
Descriptive student and school characteristics, smoking status, and beliefs among grade 10 to 12 students
in Prince Edward Island high schools (1999 & 2001)

| Demographics | | 1999 (n = 1537) | | 2001 (n = 1429) | | Chi-square |
|---|--------------------|--------------------|--------|--------------------|--------|-------------------------------------|
| | | % | (n)* | % | (n)* | |
| Gender | Female | 52.2 | (797) | 52.6 | (752) | $\chi^2 = 0.11, df = 1, p < 0.74$ |
| | Male | 47.8 | (740) | 47.3 | (677) | |
| Smoking status | Regular | 22.3 | (307) | 27.8 | (351) | $\chi^2 = 10.35, df = 1, p < 0.001$ |
| | Occasional | 21.5 | (295) | 21.5 | (272) | $\chi^2 = 0.00, df = 1, p < 0.98$ |
| | Current non-smoker | 56.2 | (772) | 50.7 | (641) | $\chi^2 = 7.93, df = 1, p < 0.01$ |
| Misperception of youth smoking prevalence | $\geq 30\%$ | 76.1 | (1163) | 60.8 | (857) | $\chi^2 = 80.25, df = 1, p < 0.001$ |
| | $< 30\%$ | 23.9 | (365) | 39.2 | (553) | |
| See students smoking near school | Yes | 98.9 | (1488) | 94.8 | (1336) | $\chi^2 = 42.57, df = 1, p < 0.001$ |
| See teachers/staff smoking near school | Yes | 26.9 | (404) | 17.7 | (249) | $\chi^2 = 35.44, df = 1, p < 0.001$ |
| In this school there are clear smoking rules | Yes | 86.3 | (1293) | 94.1 | (1322) | $\chi^2 = 49.68, df = 1, p < 0.001$ |
| If students break the rules they get in trouble | Yes | 74.1 | (1107) | 80.9 | (1136) | $\chi^2 = 18.95, df = 1, p < 0.001$ |
| Students smoke where not allowed at school | Yes | 60.9 | (912) | 62.1 | (869) | $\chi^2 = 0.43, df = 1, p < 0.51$ |
| Students asked age when buying cigarettes† | Yes | 54.1 | (226) | 48.9 | (202) | $\chi^2 = 2.21, df = 1, p < 0.14$ |
| Number of smokers in home | 1 or > | 51.2 | (784) | 45.9 | (634) | $\chi^2 = 8.16, df = 1, p < 0.001$ |
| | None | 48.8 | (746) | 54.1 | (746) | |

* Numbers may not add to total because of missing values

† Regular smokers only

TABLE 2
Logistic regression analyses examining gender, school and environmental factors associated with current non-smokers versus
occasional smokers among grade 12 students in Prince Edward Island high schools (2001)

| | | Current non-smoker (0) vs. occasional smoker (1) | | |
|---|-------------|--|--------------------|--------------------|
| | | Total (N = 831) | Females (n = 460) | Males (n = 371) |
| | | OR (95% CI) | OR (95% CI) | OR (95% CI) |
| Gender | Female | 1.38 (1.00, 1.88)* | | |
| See students smoking near school | Yes | 1.02 (0.49, 2.12) | 1.01 (0.38, 2.75) | 1.05 (0.35, 3.14) |
| | No | 1.00 | 1.00 | 1.00 |
| See teachers/staff smoke at school | Yes | 1.45 (0.94, 2.25) | 1.74 (0.93, 3.24) | 1.33 (0.71, 2.52) |
| | No | 1.00 | 1.00 | 1.00 |
| In this school there are clear smoking rules | Yes | 1.15 (0.55, 2.43) | 1.63 (0.56, 4.75) | 0.87 (0.30, 2.50) |
| | No | 1.00 | 1.00 | 1.00 |
| If students break the rules they get in trouble | Yes | 1.03 (0.67, 1.56) | 1.25 (0.71, 2.18) | 0.83 (0.43, 1.60) |
| | No | 1.00 | 1.00 | 1.00 |
| Students smoke where not allowed at school | Yes | 1.21 (0.86, 1.69) | 1.58 (1.02, 2.47)* | 0.87 (0.52, 1.47) |
| | No | 1.00 | 1.00 | 1.00 |
| Misperception of youth smoking prevalence | $\geq 30\%$ | 1.22 (0.88, 1.69) | 1.44 (0.93, 2.25) | 0.96 (0.59, 1.58) |
| | $< 30\%$ | 1.00 | 1.00 | 1.00 |
| Number of smokers in the home | 1 or > | 0.96 (0.70, 1.32) | 1.10 (0.72, 1.68) | 0.86 (0.53, 1.41) |
| Number of close friends who smoke | 1 or > | 2.57 (1.86, 3.56)† | 2.99 (1.94, 4.61)† | 2.11 (1.29, 3.46)† |

* Estimate is significantly different from estimate for reference category ($p < 0.05$)

† Estimate is significantly different from estimate for reference category ($p < 0.001$)

TABLE 3
Logistic regression analyses examining gender, school and environmental factors associated with occasional versus regular smokers among grade 12 students in Prince Edward Island high schools (2001)

| | | Occasional smoker (0) vs. regular smoker (1) | | |
|---|--------|--|----------------------|----------------------|
| | | Total (N = 563) | Females (n = 302) | Males (n = 261) |
| | | OR (95% CI) | OR (95% CI) | OR (95% CI) |
| Gender | Female | 0.58 (0.39, 0.86)* | | |
| See students smoking near school | Yes | 1.08 (0.65, 1.72) | 0.85 (0.23, 3.11) | 1.67 (0.40, 6.92) |
| | No | 1.00 | 1.00 | 1.00 |
| See teachers/staff smoke at school | Yes | 1.45 (0.94, 2.25) | 0.64 (0.32, 1.27) | 1.82 (0.89, 3.71) |
| | No | 1.00 | 1.00 | 1.00 |
| In this school there are clear smoking rules | Yes | 0.76 (0.31, 1.87) | 0.54 (0.13, 2.17) | 1.10 (0.32, 3.78) |
| | No | 1.00 | 1.00 | 1.00 |
| If students break the rules they get in trouble | Yes | 1.56 (0.89, 2.76) | 1.86 (0.88, 3.93) | 1.21 (0.49, 2.97) |
| | No | 1.00 | 1.00 | 1.00 |
| Students smoke where not allowed at school | Yes | 1.02 (0.67, 1.56) | 1.34 (0.76, 2.35) | 0.70 (0.36, 1.34) |
| | No | 1.00 | 1.00 | 1.00 |
| Misperception of youth smoking prevalence | ≥ 30% | 1.28 (0.83, 1.97) | 1.48 (0.79, 2.76) | 1.14 (0.62, 2.09) |
| | < 30% | 1.00 | 1.00 | 1.00 |
| Number of smokers in the home | 1 or > | 2.58 (1.76, 3.79)† | 2.48 (1.49, 4.14)† | 2.63 (1.45, 4.76)† |
| Number of close friends who smoke | 1 or > | 14.47 (7.17, 29.20)† | 12.06 (4.52, 32.22)† | 17.69 (6.43, 48.67)† |

* Estimate is significantly different from estimate for reference category ($p < 0.01$)

† Estimate is significantly different from estimate for reference category ($p < 0.001$)

TABLE 4
Logistic regression analyses examining gender and school and environmental factors associated with current non-smokers versus regular smokers among Grade 12 students in Prince Edward Island high schools in 2001

| | | Current non-smoker (0) vs. regular smoker (1) | | |
|---|--------|---|------------------------|-----------------------|
| | | Total (N = 906) | Females (n = 470) | Males (n = 436) |
| | | OR (95% CI) | OR (95% CI) | OR (95% CI) |
| Gender | Female | 1.03 (0.73, 1.45)* | | |
| See students smoking near school | Yes | 0.79 (0.35, 1.83) | 0.51 (0.15, 1.82) | 1.38 (0.42, 4.56) |
| | No | 1.00 | 1.00 | 1.00 |
| See teachers/staff smoke at school | Yes | 1.78 (1.13, 2.80)† | 1.29 (0.61, 2.73) | 2.43 (1.35, 4.38)* |
| | No | 1.00 | 1.00 | 1.00 |
| In this school there are clear smoking rules | Yes | 0.87 (0.38, 2.01) | 0.99 (0.26, 3.72) | 0.87 (0.28, 2.70) |
| | No | 1.00 | 1.00 | 1.00 |
| If students break the rules they get in trouble | Yes | 1.44 (0.84, 2.45) | 1.93 (0.94, 4.10) | 1.00 (0.46, 2.19) |
| | No | 1.00 | 1.00 | 1.00 |
| Students smoke where not allowed at school | Yes | 1.28 (0.89, 1.83) | 2.32 (1.37, 3.93)† | 0.72 (0.43, 1.20) |
| | No | 1.00 | 1.00 | 1.00 |
| Misperception of youth smoking prevalence | ≥ 30% | 1.41 (0.98, 2.05) | 2.39 (1.36, 4.21)† | 0.90 (0.54, 1.49) |
| | < 30% | 1.00 | 1.00 | 1.00 |
| Number of smokers in the home | 1 or > | 2.35 (1.67, 3.30)* | 2.58 (1.56, 4.25)* | 2.17 (1.33, 3.51)* |
| Number of close friends who smoke | 1 or > | 37.46 (19.39, 72.36)* | 41.16 (16.10, 105.20)* | 36.04 (14.11, 92.05)* |

* Estimate is significantly different from estimate for reference category ($p < 0.01$)

† Estimate is significantly different from estimate for reference category ($p < 0.001$)

findings suggest that access to cigarettes for this population was high, as indicated both by students continuing to see others smoking near school property and by not regularly being asked their age when buying cigarettes. These findings support a recent study by Doubeni et al.²⁹ who reported that perceived accessibility of cigarettes increases the risk of smoking among youth. More robust studies are needed to continue to explore the role of schools³⁰ within a broader community context and to enhance systematic monitoring and surveillance for health promotion and prevention initiatives.

Additional analyses were used to better understand the increasing prevalence of smoking in this study population. For instance, when we adjusted for age in our analysis, it appears that both regular and occasional smoking rates decreased for grade 11 students during the same time period. This is consistent with our previous studies which highlighted that the prevalence of regular smoking of grade 10 and grade 12 students decreased over the three years of the study, from 20% to 15.8% and from 30.1% to 24.6%, respectively.^{24,25} This finding also supports previous studies that suggest targeting tobacco control efforts at different age groups is particularly needed in high schools where tobacco use increases with the age and grade of students.^{24,25,31}

Having close friends who smoke and having one or more smokers in the home were strongly associated with increased risk of smoking among high school students. Over the same period, the proportion of students overestimating smoking prevalence of peers and seeing students and teachers smoking near their school decreased. The existence of programs and policies in the school environment was not generally associated with smoking behaviour. Other strong reviews also showed that many factors, not just one single approach, influenced adolescent smoking^{12,17,19,32-35} and that the most effective tobacco-control campaigns use a comprehensive set of policy measures, target different populations and meet different needs.^{24,31,36} Consistent with a recent review by Sandford that suggests that there is little evidence that school-based smoking

education programs have a lasting impact on youth smoking,³⁷ we consider that a population approach using government and community interventions would better address youth smoking prevention.

The changes in the social and environmental characteristics that influence tobacco behaviour suggest that during the three years of this study there were statistically significant differences in the knowledge and perceptions about tobacco use and policy control among the students we surveyed. These findings contribute to previous research about the importance of smoking policy and adolescents' knowledge about smoking.³⁸⁻⁴⁰ However, in the logistic regression models these changes were not associated with smoking behaviour. This finding adds further support to the literature on the influence of schools and other environmental factors on smoking behaviour of youth.^{12,34,39-41}

Policies that allow smoking on or near school property appeared to be potentially detrimental to smoking control efforts within the schools. For instance, we found that seeing teachers and staff smoke near the school was associated with greater likelihood of being a regular smoker in grade 12 students. Previous research suggests that seeing smoking near the school could undermine new policies when students perceive that teachers do not practice what they teach.⁴² Additionally, female students who saw other students smoking where they were not allowed were more likely to be regular smokers. This finding contributes to previous research suggesting that strongly enforced policies are necessary for successful tobacco control.^{43,44}

As expected, the behaviour of family members and friends was strongly associated with the likelihood of being a smoker. The large odds ratio may be explained by the fact that our results are drawn from a sample of students as they move from grade 10 through to grade 12, where typical increases in smoking behaviour occur. Moreover, our findings strongly support social influences as important components of smoking prevention programs.^{24,45} A possible explanation for our findings is the

important influence of social friendships on smoking behaviour during high school.⁴⁶ The relationship between smoking behaviour and close friendships is strongly linked to the type of friendships and how these friends influence behaviour.^{9,11} The smoking behaviour of family members was also a strong trigger for regular smoking behaviour. However, developing effective family programs that target adolescent smoking within schools has been challenging.⁴⁷ Family-level interventions developed for elementary school students⁴⁸⁻⁵⁰ or community-based programs⁵¹⁻⁵² are often not appropriate for high school students. New research that brings families and youth together to address tobacco-control programming for students who are regular smokers may contribute to important lessons in tobacco control.

Having more close friends who smoke was a strong influence on the smoking behaviour of both male and female students. Existing literature suggests some gender differences in social influences, although conflicting results indicate no clear pattern.^{12,13,53,54} This study showed that there was a substantial influence of close friends' smoking behaviour between occasional and regular smoking for both male and female students. A possible explanation is that by grade 12 both male and female students are experiencing strong pressure to smoke. Providing strong policy enforcement and negative messages about smoking behaviour may contribute to a cost-effective intervention; how to alter the influence of close friends who smoke is more problematic. Creating an environment for the most susceptible students in which smoking is viewed and modeled negatively is likely to be a key factor in their future behaviour. Recruiting the help of influential persons and role models to send powerful messages about what is normal and accepted in regard to smoking within a particular school may be a possible strategy.²³ For example, some students who smoke and are considered role models in the school may be able to play a role in helping other smoking students join cessation programs and/or prevention programming for those who have not transitioned to regular smoking.

Limitations of the study

This study is subject to limitations. Self-reported surveys were used where the validity of the responses is questionable. Since we used sealed envelopes for the student surveys to assure anonymity and confidentiality of responses, we cannot account for students who failed a grade and may have answered the questionnaire during the repeat year, who may have answered the questionnaire one year but not the next, who left the school for other reasons and who were new to the grade that year. The small number of high schools (ten) within the province was insufficient to conduct higher level analyses at the school level. Classroom level analysis could not be completed because of variability in the class level data collection procedures. Students' self reports on the smoking behaviour of their friends may have overestimated their smoking influence. Without ongoing surveillance of multiple factors that influence smoking behaviour, we cannot answer questions about what else might have been happening in schools or communities that may have accounted for the observed changes. Some other initiatives and events were happening locally and nationally over the course of the study; however, without systematic data collection we are unable to suggest any causality. Large studies that can compare across regions within the province and possibly target subpopulations might provide more robust data for informing policy and programs.

Conclusion

The school tobacco-control programs and policies implemented in PEI did not appear to affect the smoking behaviour of students by the time they were in grade 12, though students showed a significant increase in their knowledge and awareness of the tobacco policy and beliefs about it and its enforcement. Family and close friends were the social and environmental influences on the smoking behaviour of this population of youth, suggesting that programs and policies associated with banning smoking and enforcing smoking restrictions at school alone may not work unless they also adequately address the influence of smoking peers and family

members and broader contextual environmental influences. While synergies within the comprehensive tobacco strategy may account for the overall decrease in smoking rates in the province, factors other than policy and program sentiments may have played a large part in the increase of tobacco use for this sample of students. Additional longitudinal research with larger populations, more schools, and linked student data may address these concerns more fully.

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References

1. Clark W. Youth smoking in Canada. *Can Social Trends*. 1996;43(winter): 2-6.
2. Chen J. Age at diagnosis of smoke related disease. *Health Rep*. 2003;14(2):9-19.
3. Health Canada. Smoking and your body: Health effects of smoking. Ottawa: Health Canada; 2009. Available from: http://www.hc-sc.gc.ca/hl-vs/tobac-tabac/body-corps/index_e.html
4. Health Canada. Youth Smoking Survey - 2004-2005. Ottawa: Health Canada; 2007. Available from: http://www.hc-sc.gc.ca/hc-ps/tobac-tabac/research-recherche/stat/survey-sondage_2004-2005-eng.php
5. Health Canada. Youth Smoking Survey - 2004-2005. Table 6: Ever tried smoking a cigarette, by province and grade, all grades, 2004-05. [Internet]. Ottawa: Health Canada; 2007. Available from: http://www.hc-sc.gc.ca/hc-ps/tobac-tabac/research-recherche/stat/_survey-sondage_2004-2005/table-6-eng.php
6. Health Canada. Youth Smoking Survey - 2004-2005. Table 2: Smoking status by sex and grouped grades, all grades, Canada, 2004-05. Ottawa: Health Canada; 2007. Available from: http://www.hc-sc.gc.ca/hc-ps/tobac-tabac/research-recherche/stat/_survey-sondage_2004-2005/table-2-eng.php
7. Health Canada. Smoking prevalence 1999-2007. Canadian Tobacco Use Monitoring Survey (CTUMS) Smoking Prevalence 1999-2008 Wave 1. Ottawa: Health Canada; 2008. Available from: http://www.hc-sc.gc.ca/hc-ps/tobac-tabac/research-recherche/stat/_ctums-esutc_prevalence/prevalence-eng.php
8. Prince Edward Island Department of Health. 2007 PEI Student Drug Survey: Highlights Report. Charlottetown (PE): Government of Prince Edward Island; 2007. Available from: http://www.gov.pe.ca/photos/original/doh_sds_hl_eng.pdf
9. Mercken L, Candel M, Willems P, de Vries H. Disentangling social selection and social influence effects on adolescent smoking: the importance of reciprocity in friendships. *Addiction*. 2007;102(9):1483-92.
10. De Vries H, Mudde AN, Dijkstra A, Willemsen MC. Differential beliefs, perceived social influences and self-efficacy expectations among smokers in various motivational phases. *Prev Med*. 1998;27(5 pt 1):681-9.
11. De Vries H, Candel M, Engels R, Mercken L. Challenges to the peer influence paradigm: results for the 12-13 year olds from six European countries from the European Smoking Prevention Framework Approach Study. *Tob Control*. 2006;15(2):83-9.

12. Tyas SL, Pederson L. Psychosocial factors related to adolescent smoking: a critical review of the literature. *Tob Control*. 1998;7(4):409-20.
13. Chassin L, Presson CC, Sherman SJ, Montello D, McGrew J. Changes in peer and parent influence during adolescence: Longitudinal versus cross-sectional perspectives on smoking initiation. *Dev Psychol*. 1986;22(3):327-4.
14. Unger JB, Chen X. The role of social networks and media receptivity in predicting age of smoking initiation: a proportional hazards model of risk and protective factors. *Addict Behav*. 1999;24(3):371-81.
15. Kaiserman M, McDonald PW. Overview and Conclusion. 2002 Youth Smoking Survey - Technical Report. Ottawa: Health Canada; 2007. Available from: <http://www.hc-sc.gc.ca/hc-ps/pubs/tobac-tabac/yss-etj-2002/chap13-eng.php>
16. Schofield MJ, Lynagh M, Mishra G. Evaluation of a Health Promoting Schools program to reduce smoking in Australian secondary schools. *Health Educ Res*. 2003;18(6):678-92.
17. Biglan A, Ary DV, Smolkowski K, Duncan T, Black C. A randomized controlled trial of a community intervention to prevent adolescent tobacco use. *Tob Control*. 2000;9(1):24-32.
18. Orleans CT, Cummings KM. Population-based tobacco control: progress and prospects. *Am J Health Promot*. 1999;14(2):83-91.
19. Cameron R, Brown KS, Best JA, Pelkman CL, Madill CL, Manske SR, Payne ME. Effectiveness of a social influences smoking prevention program as a function of provider type, training method, and school risk. *Am J Public Health*. 1999;89(12):1827-31.
20. Chassin L, Presson CC, Todd M, Rose JS, Sherman SJ. Maternal socialization of adolescent smoking: the intergenerational transmission of parenting and smoking. *Dev Psychol*. 1998;34(6):1189-201.
21. Wilkinson D, Abraham C. Constructing an integrated model of the antecedents of adolescent smoking. *Br J Health Psychol*. 2004;9(pt 3):315-33.
22. Currie C, Roberts C, Morgan A, Smith R, Settertobulte W, Samdal O, Barnkow Rasmussen V, editors. Young people's health in context. Health Behaviour in School-aged Children (HSBC) Study: international report from 2001/02 survey. Copenhagen: World Health Organization; 2004. Available from: <http://www.hbsc.org/publications/reports.html>
23. Wiium N, Wold B. Family and social influences on adolescent smoking behaviour. *Health Educ*. 2006;106(6):465-79.
24. Murnaghan D, Sihvonen M, Leatherdale S, Kekki P. The relationship between school-based smoking policies and prevention programs on smoking behavior among grade 12 students in Prince Edward Island: a multi level analysis. *Prev Med*. 2007;44(4):317-322.
25. Murnaghan D, Leatherdale S, Sihvonen M, et al. A multi-level analysis examining the association between school-based smoking policies, prevention programs and youth smoking behavior: evaluating a provincial tobacco control strategy. *Health Educ Res*. 2008;23(6):1016-28.
26. Cameron R, Manske S, Brown KS, et al. Integrating public health policy, practice, evaluation, surveillance, and research: the school health action planning and evaluation system. *Am J Public Health*. 2007;97(4):648-54.
27. Statistical Package Social Sciences, 15.0. The SPSS System for Windows. SPSS Inc., 2008.
28. Leatherdale ST, Cameron R, Brown KS, Jolin MA, Kroeker C. The influence of friends, family and older peers on smoking among elementary school students: low risk students in high risk schools. *Prev Med*. 2006;42(3):218-222.
29. Doubeni CA, Li W, Fouayzi MS, Difranza JR. Perceived Accessibility as a predictor of youth smoking. *Ann Fam Med*. 2008;6(4):323-30.
30. Sussman S. School-based tobacco use prevention and cessation: where are we going? *Am J Health Behav*. 2001;25(3):191-9.
31. Leatherdale ST, Cameron R, Brown KS, et al., Senior student smoking at school, student characteristics and smoking onset among junior students; a multilevel analysis. *Prev Med*. 2005;40(6):853-9.
32. Griesbach D, Inchley J, Currie C. More than words? The status and impact of smoking policies in Scottish schools. *Health Promot Int*. 2002;17:31-41.
33. U.S. Department Health and Human Services. Reducing Tobacco Use: A Report of the Surgeon General. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; 2000.
34. Stead M, Hastings G, Tudor-Smith C. Preventing adolescent smoking: A review of the options. *Health Educ J*. 1996;55(1):31-54.
35. Reid DJ, McNeill AD, Glynn TJ. Reducing the prevalence of smoking in youth in western countries: An international review. *Tob Control*. 1995;4(3):266-77.
36. Chaloupka F, Teh-wei H, Warner KE, van der Merwe R, Yurekli A. The taxation of tobacco products. In Jha P, Chaloupka FJ, editors. Tobacco control in developing countries. New York: Oxford University Press; 2000. p. 237-272.
37. Sandford A. Trends in smoking among adolescents and young adults in United Kingdom: Implications for health education. *Health Educ*. 2008;108(3):223-36.
38. Pentz MA, Brannon BR, Charlin VL, Barrett EJ, MacKinnon DP, Flay BR. The power of policy: The relationship of smoking policy to adolescent smoking. *Am J Public Health*. 1989;79(7):857-862.

39. Maes L, Lievens J. Can the school make a difference? a multilevel analysis of adolescent risk and health behavior. *Soc Sci Med* 2003;56:517-529.
40. Wakefield MA, Chaloupka FJ, Kaufman NJ, Orleans CT, Barker DC, Ruel EE. Effects of restrictions on smoking at home, at school and in public places on teenage smoking: Cross sectional study. *BMJ*. 2000;321(7257):333-7.
41. Lantz PM, Jacobson PD, Warner KE, Wasserman J, Pollack HA, Berson J, Ahlstrom A. Investing in youth tobacco control: a review of smoking prevention and control strategies. *Tob Control*. 2000; 9(1):47-63.
42. Kumar R, O'Malley P, Johnston L. School tobacco control policies related to student smoking and attitudes toward smoking: national survey results, 1999-2000. *Health Educ Behav*. 2005;32(6):780-94.
43. Moore L, Roberts C, Tudor-Smith C. School smoking policies and smoking prevalence among adolescents: multilevel analysis of cross-sectional data from Wales. *Tob Control*. 2001;10(2):117-23.
44. Lovato CY, Sabiston CM, Hadd V, Nykiforuk CI, Campbell HS. The impact of school smoking policies and student perceptions of enforcement on school smoking prevalence and location of smoking. *Health Educ Res*. 2007;22(6):782-793.
45. Leatherdale ST, McDonald PW, Cameron R, Brown KS. A multilevel analysis examining the relationship between social influences for smoking and smoking onset. *Am J Health Behav*. 2005;29(6):520-30.
46. Pärna K, Rahu K, Fischer K, Mussalo-Rauhamaa H, Zhuravleva I, Umbleja T, Rahu M. Smoking and associated factors among adolescents in Tallinn, Helsinki and Moscow: a multilevel analysis. *Scand J Public Health*. 2003;31(5):350-8.
47. Thomas RE, Baker P, Lorenzetti D. Family-based programmes for preventing smoking by children and adolescents. *Cochrane Database Syst Rev*. 2007;4:1-44. Available from: <http://www.mrw.interscience.wiley.com/cochrane/clsystrev/articles/CD004493/frame.html>
48. Elder JP, Perry CL, Stone EJ, Johnson CC, Yang M, Edmundson EW, Smyth MH, Galati T, Feldman H, Cribb P, Parcel GS. Tobacco use measurement, prediction and intervention in elementary schools in four states: The CATCH Study. *Prev Med*. 1996;25(4):486-94.
49. Nutbeam D, Macaskill P, Smith C, Simpson JM, Catford J. Evaluation of two school smoking education programmes under normal classroom conditions. *BMJ*. 1993; 306(6870):102-7.
50. Tingen MS, Waller JL, Smith MT, Baker RR, Reyes J, Treiber FA. Tobacco prevention in children and cessation in family members. *J Am Acad Nurse Pract*. 2006;18(4):169-79.
51. Mahabee-Gittens EM, Huang B, Slap GB, Gordon JS. An emergency department intervention to increase parent-child tobacco communication: A pilot study. *J Child Adolesc Subst Abuse*. 2008;17(2):71-83.
52. Jones DJ, Foster SE, Olson AL, Forehand RL, Gaffney CA, Zens MS, Bau JJ. Longitudinal retention of families in the assessment of a prevention program targeting adolescent alcohol and tobacco: the utility of an ecological systems framework. *Behav Modif*. 2007;31(5):638-59.
53. Flay BR, Hu FB, Siddiqui O, Day LE, Hedeker D, Petraitis J, Richardson J, Sussman S. Differential influence of parental smoking and friends' smoking on adolescent initiation and escalation of smoking. *J Health Soc Behav*. 1994;35(3):248-65.
54. Hoffman B, Sussman S, Unger JB, Valente TW. Peer influences on adolescent cigarette smoking: A theoretical review of the literature. *Subst Use Misuse*. 2006; 41(1):103-5

A deprivation index for health planning in Canada

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Abstract

Administrative databases in the Canadian health sector do not contain socio-economic information. To facilitate the monitoring of social inequalities for health planning, this study proposes a material and social deprivation index for Canada. After explaining the concept of deprivation, we describe the methodological aspects of the index and apply it to the example of premature mortality (i.e. death before the age of 75). We illustrate variations in deprivation and the links between deprivation and mortality nationwide and in different geographic areas including the census metropolitan areas (CMAs) of Toronto, Montréal and Vancouver; other CMAs; average-size cities, referred to as census agglomerations (CAs); small towns and rural communities; and five regions of Canada, namely Atlantic, Quebec, Ontario, the Prairies and British Columbia. Material and social deprivation and their links to mortality vary considerably by geographic area. We comment on the results as well as the limitations of the index and its advantages for health planning.

Key words: Social inequalities, deprivation, health, health planning, premature mortality, Canada, geographical areas, metropolitan areas, urban areas, regions

Introduction

At a recent Canadian conference on health indicators, the participants proposed a list of 150 indicators as a means of giving the public, care providers and health authorities reliable and comparable data on health and the health system.¹ The participants also pointed out the need to report on inequalities in health, especially those resulting from socio-economic status and urban or rural location of residence.

Since the late 1970s, the production of health surveys such as the Canada Health Survey,² the National Population Health Survey (NPHS)³ and the Canadian Community Health Survey (CCHS)⁴ have addressed this need. They contain general measures of health and health service

use, as well as information on income, education, family structure and other socio-economic characteristics of respondents which can easily be cross-tabulated. The same cannot be said of the administrative databases created by provincial authorities to track the progression of vital statistics, such as mortality, or the use of health services, such as hospital admissions and primary care; these databases contain no socio-economic data on the individuals concerned.

To make up for this shortcoming, researchers generally use geographic proxies. These pieces of socio-economic information relate to small areas that can be introduced into administrative databases by linking these areas to the data available in the databases. This approach was initiated in

Great Britain⁵ and then introduced to other countries,⁶⁻⁸ including Canada.⁹⁻¹³

All the Canadian studies that have used geographic proxies tracked social inequalities in health, generally using mortality as a health indicator, although some also considered measures of morbidity and use of health services. These analyses have also largely focused on urban areas and have tended to use only one indicator of social disparity—neighbourhood income.

The contribution made by these studies is undeniable. However, while income is a powerful indicator of health and has ramifications for other determinants of health, it cannot take the place of all those other determinants.^{14,15} This is why more complex measures, namely deprivation indexes, have been developed in Great Britain¹⁶⁻²³ and elsewhere in Europe (Sweden,²⁴ Italy,²⁵ Spain,²⁶ France²⁷), as well as in the United States,^{7,28,29} Japan³⁰ and New Zealand.³¹ Such indexes cover a wide range of domains, from material deprivation alone^{17,20,23} to seven separate domains, including income, employment, health, education, crime, housing and living environment.²² Such indexes have already been proposed in Canada, namely in Manitoba and Quebec, and in the metropolitan area of Vancouver.³²⁻³⁵ They vary substantially in content and design and none covers Canada as a whole.

The deprivation index developed in Quebec has been widely used in the health sector. Since 2000, it has been introduced into a

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dozen administrative databases covering mortality, births, hospital admissions, medical services, nursing homes, youth protection services, clients of *Centres Locaux de Services Communautaires* (CLSCs) and community organizations.^{34,36-44} The index is also being used for regional resource allocation in Quebec⁴⁰ and is associated with various products (for example, SAS program used to assign the index, population tables based on the index, interactive index mapping, etc.) that are available free of charge on the Internet.⁴⁵

We propose a national version of the deprivation index developed in Quebec. Our goal is to describe the conceptual and methodological bases of the index, to explore its validity and variations according to geographic areas that reflect Canada's diversity, and to illustrate its use in health planning through a single example—premature mortality.

We begin by defining the concept of deprivation and go on to describe the data and methods that are the foundation of the index. We present the results in relation to premature mortality and discuss the advantages of using the index in health planning.

The concept of deprivation

In the mid-1980s, Peter Townsend proposed a definition of deprivation as "a state of observable and demonstrable disadvantage relative to the local community or the wider society or nation to which an individual, family or group belongs."⁴⁶ This disadvantage may occur at various levels, for example, with regard to food, housing, education, work or social ties. A person is considered deprived if he or she falls below the level attained by the majority of the population or below what is considered socially acceptable. Townsend distinguishes two forms of deprivation: material and social. Material deprivation involves deprivation of the goods and conveniences that are part of modern life, such as adequate housing, a car, a television set, or a neighbourhood with recreational

areas. Social deprivation refers to relations within the family and in the workplace and community.

This idea of deprivation is related to a number of other concepts. Material deprivation evokes the concept of poverty,⁴⁷ as in a lack of financial resources. For Townsend, however, poverty leads to deprivation in that it stands in the way of the acquisition of the goods and conveniences that are part of modern life. Social deprivation is related to the concept of social capital⁴⁷ and associated concepts, such as social fragmentation⁴⁸ and social isolation.⁴⁹ In all cases, it is a question of the type of social interactions (mutual trust and help, for example), as well as the intensity and quality of such interactions.

In summary, what we need to retain from Townsend's definition is that deprivation cannot be reduced to a single material or economic dimension; it must also take into account social interactions.

Data and methodology

Basic spatial unit

The deprivation index is based on a spatial unit. Since the index is intended as a substitute for measures of individuals, the selected unit must be as small as possible in order to ensure a high degree of homogeneity in the socio-economic conditions attributed to each resident in this unit.⁶ The selected unit is the dissemination area (DA),⁵⁰ which comprises one or more neighbouring blocks of houses, with a population of 400 to 700 persons.

We constructed the index in two stages. In the first stage, we set aside DAs comprising no population, DAs with a high proportion of collective households or institutionalized persons (more than 15% of the total population or over 80 people living in collective households), DAs that had no B profile (socio-economic) or income data (sparsely populated DAs), and DAs in Nunavut Territory or located on a First Nations reserve. This left 42 430 DAs

covering slightly more than 93% of the Canadian population. In the second stage, we projected the obtained deprivation values onto an additional number of DAs, including the DAs for which it was possible to adequately impute* an income value (3572 DAs); the DAs located in Nunavut and on First Nations reserves with a complete B profile or imputed income value (857 DAs); and DAs that had been excluded due to their high proportion of collective households or institutionalized persons but whose population with a B profile (or imputed income) accounted for more than 85% of the total population (605 DAs). As a result, a deprivation index was established for 47 464 DAs, or close to 98% of the population of Canada.

Socio-economic indicators

The indicators used to construct the index were selected on the basis of a literature review. To be selected, indicators needed to meet four criteria: have known links with health, previous use as geographic proxies, affinity with the material or social dimensions of deprivation, and availability by DA.^{5,14,15,23,35,49,51,52} This approach made it possible to identify the six indicators that were taken into account to construct the index: the proportion of people aged 15 years and older with no high school diploma (SCOLAR); the employment/population ratio of people aged 15 years and older (EMPLOI); the average income of people aged 15 years and older (REVENU); the proportion of individuals aged 15 years and older living alone (SEULES); the proportion of individuals aged 15 years and older who are separated, divorced or widowed (S_D_V); and the proportion of single-parent families (F_MONO).[†]

In some instances, the selected indicators varied significantly with the age and sex of the population. This was true of education, for example, since many young people less than 20 years old have not completed their schooling while many older people have a low level of education. Since the variations being tracked are socio-economic rather than demographic, these indicators, with

* Imputation of income was by the nearest-neighbour method, based on the Euclidian distance between the other indicators (other than income) included in the deprivation index, using the SAS FASTCLUS procedure.

† Families include couples with or without children and single parents with at least one child.⁵⁰

the exception of F_MONO, were adjusted according to the age-sex structure of the Canadian population⁵¹ using direct standardization.⁵³ Moreover, certain indicators were transformed in order to normalize their distribution.⁵⁴ For example, the REVENU variable was transformed into its log values and the SEULES variable into its arcsine values.

Integration of indicators

The integration of indicators in the form of a deprivation index was carried out using principal component analysis (PCA), the preferred approach for developing such indexes.^{25-29,31,49,55} This analysis yields fewer dimensions, reflecting the spatial organization of socio-economic indicators. A varimax rotation was applied to these dimensions to increase readability and to make them independent (or orthogonal). To validate the relevance of this factor structure across Canada, the PCA was repeated for the three largest census metropolitan areas (major CMAs), Toronto, Montréal and Vancouver; various other geographic areas, namely other CMAs, census agglomerations (CAs), small towns and rural communities; and each of five regions, Atlantic, Quebec, Ontario, the Prairies and British Columbia. The literature shows that measures of deprivation perform differently in urban and rural settings.^{52,56-60}

For each component identified, the PCA produces a factor score which represents the value of the component in each DA. To ensure statistical accuracy in analyzing social inequalities in health, the DAs were grouped together. The DAs were first ranked according to their factor score from the most to the least privileged. Then, the distribution of DAs was broken down into quintiles, with each quintile representing 20% of the population. Quintile 1 (Q1) represents the most privileged population and quintile 5 (Q5), the least. These operations were carried out separately for each component of the analysis. Since deprivation is seen as a relative disadvantage compared with the community to which people belong, different versions of the index were produced by modifying the reference territory. Accordingly, there is a national version, a version by major CMA, a version by geographic area and a version

by region. These versions are based on the PCA conducted in each setting and on the distribution of factor scores, ensuring an equal distribution of the population (20%) per material and social quintile.

Any of these versions can be used to reflect the discrepancies in deprivation that exist in each setting and also to compare populations of the same proportion. In the following analysis, the version of the index varies according to the reference territory considered. The values presented for Canada as a whole stem from the national version. Those presented for the geographic areas, major CMAs and regions of Canada stem from the geographic area, major CMA, and region of Canada versions, respectively.

Premature mortality

To illustrate how the index can be used to study socio-economic indicators of health for the purpose of health planning, we use the example of premature mortality, or death before 75 years of age. This is a general measure of population health¹ whose relationships with socio-economic conditions have been extensively documented on an international scale.⁶¹⁻⁶⁶

Taking into account deaths in 2001 and using the reference population from the census of the same year, we estimated the mortality rates using the negative binomial regression model, a generalization of the Poisson regression model that takes into account the problem of over-dispersion.⁶⁷ We estimated models in each geographic area for all deaths (all causes combined) and the entire population (both sexes combined). In these models, mortality rates were estimated for each quintile of material and social deprivation, from the most privileged (Q1) to the most deprived (Q5), and for the extreme quintiles on both dimensions (Q1-Q1 and Q5-Q5), adjusting for age, sex and, where applicable, geographic area and the other form of deprivation (material or social). Thus, when the mortality rate varies with both forms of deprivation simultaneously, this signifies that each form of deprivation is contributing to mortality independently. An interaction term between the two forms of deprivation was introduced into the models when a significance threshold

of 5% was reached. The variability of adjusted rates was estimated using the Delta method.⁶⁸

To obtain a satisfactory portrait of the inequalities in mortality according to deprivation, we considered three measures: the adjusted mortality rate, the ratio, and the difference in adjusted mortality rates.⁶⁹⁻⁷¹ The mortality rate (per 100 000 inhabitants) expresses the level of mortality in each group. The ratio and the difference in the mortality rates illustrate, respectively, the relative and absolute discrepancies in mortality rates between groups at the extreme ends of the deprivation spectrum. Taking both forms of deprivation into consideration simultaneously, the mortality ratio is obtained by dividing the rate for the most deprived group (Q5-Q5) by that of the most privileged group (Q1-Q1). The difference in mortality is obtained by subtracting the rate for the most privileged group (Q1-Q1) from that of the most deprived group (Q5-Q5).

Results

The deprivation index

The deprivation index covers almost 98% of the Canadian population, and this percentage varies little from one geographic area to the next (Table 1). The index covers close to 90% of DAs in Canada, with a higher proportion of DAs in CMAs than in smaller towns and rural communities. This discrepancy is due to the greater number of DAs with no population in smaller towns and rural communities.

The Canada-wide PCA reveals the presence of a two-component factor structure (Table 2). Each of these components summarizes approximately one-third of the variations associated with the six indicators considered, for a total of 67% of these variations. The meaning of the components differs considerably. Whereas the first component primarily portrays variations associated with education, employment and income, the second indicates the state of being separated, divorced or widowed, living alone, or being a member of a single-parent family. This configuration echoes Townsend's material and social dimensions of deprivation.⁶⁶ For this reason, and to

TABLE 1
Population and dissemination areas (DAs) covered by the deprivation index by geographic area and region of Canada, 2001

| | Population | | | DA | | | Average population† |
|-----------------------------------|------------|------------|------|--------|---------|------|------------------------|
| | Total | Covered | | Total | Covered | | |
| | n | n | % | n | n | % | n |
| Area* | | | | | | | |
| Major CMAs | 11 159 876 | 10 881 733 | 97.5 | 17 962 | 17 297 | 96.3 | 629 |
| Other CMAs | 8 137 050 | 7 913 022 | 97.2 | 13 357 | 12 697 | 95.1 | 623 |
| CAs | 4 542 160 | 4 446 726 | 97.9 | 6 921 | 6 088 | 88.0 | 730 |
| Small towns and rural communities | 6 168 008 | 6 070 620 | 98.4 | 14 753 | 11 382 | 77.2 | 533 |
| Region | | | | | | | |
| Atlantic | 2 285 729 | 2 256 726 | 98.7 | 4 202 | 3 526 | 83.9 | 640 |
| Quebec | 7 237 479 | 7 074 786 | 97.8 | 12 153 | 11 208 | 92.2 | 631 |
| Ontario | 11 410 046 | 11 132 340 | 97.6 | 18 596 | 17 212 | 92.6 | 647 |
| Prairies | 5 073 323 | 4 950 516 | 97.6 | 10 315 | 8 902 | 86.3 | 556 |
| British Columbia | 3 907 738 | 3 806 636 | 97.4 | 7 463 | 6 448 | 86.4 | 542 |
| Canada | 30 007 094 | 29 312 101 | 97.7 | 52 993 | 47 464 | 89.6 | 618 |

* Approximate populations by geographic area: the major census metropolitan areas (CMAs), 2 000 000 or more; the other CMAs, between 100 000 and 1 000 000; the census agglomerations (CAs), between 10 000 and 100 000; and small towns and rural communities, less than 10 000.

† Average population of dissemination areas in the geographic area or region of Canada.

Source: 2001 Census of Canada.

TABLE 2
Principal components of the deprivation index in Canada

| Indicator | Component | |
|---------------------|-----------|--------|
| | Material | Social |
| SCOLAR* | -0.83 | 0.00 |
| EMPLOI† | 0.71 | -0.19 |
| REVENU‡ | 0.82 | -0.27 |
| SEULES§ | -0.01 | 0.84 |
| S_D_V | -0.16 | 0.87 |
| F_MONO¶ | -0.34 | 0.65 |
| Explained variance | 34% | 33% |
| Cumulative variance | 34% | 67% |

* Ratio of individuals 15 years and older with no high school diploma to the population 15 years and older

† Ratio of individuals 15 years and older who are employed to the population 15 years and older

‡ Average personal income for the population 15 years and older

§ Ratio of individuals 15 years and older living alone to the population 15 years and older

|| Ratio of individuals 15 years and older who are separated, divorced or widowed to the population 15 years and older

¶ Ratio of single-parent families to the total number of families

NOTE: The above values are saturations. They should be interpreted as correlation coefficients between the indicator and the component.

Source: 2001 Census of Canada.

facilitate the ensuing analysis and discussion, these two components will be referred to as material and social. The PCAs carried out in the different geographic areas and regions of Canada show that these two components were present everywhere, with the exception that the proportion of

single-parent families in CMAs is associated with both material and social components equally (Table 3 and Table 4). The explained variance for both components is only slightly lower in small towns and rural communities and decreases from east to west across the country.

Material and social deprivation in Canada

The deprivation index reveals appreciable discrepancies in socio-economic conditions in Canada (Table 5). Material deprivation is accompanied by well-recognized variations in education, employment and income and, to a lesser degree, single-parent families. Social deprivation is more prevalent with single-parent families, with people living alone, and with those who are separated, divorced or widowed. This form of deprivation is also not totally independent of employment and income, as well as a certain degree of population aging, even though the indicators considered have been adjusted for age. By combining the two forms of deprivation and comparing the most privileged population (Q1 and Q1) with the least privileged population (Q5 and Q5) on both the material and social dimensions simultaneously, we note startling contrasts for all indicators that make up the deprivation index.

Such contrasts are observed across Canada, regardless of the geographic area or region (Table 6). However, the magnitude of socio-economic disparities can vary by area or region. The discrepancies in material and social deprivation are generally greater in the major CMAs than in census

TABLE 3
Principal components of the deprivation index by geographic area

| Indicator | Major CMAs | | | | | | Other CMAs | | CAs | | Small towns, rural communities | |
|---------------------|------------|--------|----------|--------|-----------|--------|------------|--------|-----------|----------|--------------------------------|--------|
| | Toronto | | Montréal | | Vancouver | | Component | | Component | | Component | |
| | Material | Social | Material | Social | Material | Social | Material | Social | Social | Material | Material | Social |
| SCOLAR* | -0.91 | 0.10 | -0.84 | 0.09 | -0.81 | -0.11 | -0.85 | -0.01 | 0.15 | -0.77 | -0.78 | -0.04 |
| EMPLOI† | 0.67 | -0.13 | 0.73 | -0.19 | 0.65 | 0.00 | 0.67 | -0.23 | -0.17 | 0.77 | 0.75 | -0.23 |
| REVENU‡ | 0.85 | -0.17 | 0.84 | -0.25 | 0.84 | -0.20 | 0.78 | -0.35 | -0.33 | 0.80 | 0.85 | -0.03 |
| SEULES§ | 0.12 | 0.87 | -0.08 | 0.86 | 0.10 | 0.87 | -0.04 | 0.89 | 0.84 | -0.14 | 0.04 | 0.79 |
| S_D_V | -0.25 | 0.84 | -0.18 | 0.82 | -0.10 | 0.90 | -0.30 | 0.84 | 0.88 | -0.21 | -0.02 | 0.85 |
| F_MONO# | -0.57 | 0.54 | -0.44 | 0.63 | -0.49 | 0.48 | -0.52 | 0.56 | 0.72 | -0.32 | -0.23 | 0.68 |
| Explained variance | 37% | 30% | 36% | 32% | 34% | 31% | 35% | 33% | 36% | 33% | 33% | 31% |
| Cumulative variance | 37% | 67% | 36% | 68% | 34% | 65% | 35% | 68% | 36% | 69% | 33% | 64% |

* Ratio of individuals 15 years and older with no high school diploma to the population 15 years and older

† Ratio of individuals 15 years and older who are employed to the population 15 years and older

‡ Average personal income for the population 15 years and older

§ Ratio of individuals 15 years and older living alone to the population 15 years and older

|| Ratio of individuals 15 years and older who are separated, divorced or widowed to the population 15 years and older

Ratio of single-parent families to the total number of families

NOTE: The above values are saturations. They should be interpreted as correlation coefficients between the indicator and the component. When each component explains essentially the same percentage of the total variance, their position can be inverted.

Source: 2001 Census of Canada.

TABLE 4
Principal components of the deprivation index by region of Canada

| Indicator | Atlantic | | Quebec | | Ontario | | Prairies | | British Columbia | |
|---------------------|-----------|--------|-----------|--------|-----------|--------|-----------|----------|------------------|----------|
| | Component | | Component | | Component | | Component | | Component | |
| | Material | Social | Material | Social | Material | Social | Social | Material | Social | Material |
| SCOLAR* | -0.89 | -0.01 | -0.84 | -0.05 | -0.82 | -0.02 | -0.05 | -0.86 | -0.02 | -0.80 |
| EMPLOI† | 0.85 | 0.00 | 0.77 | -0.17 | 0.66 | -0.24 | -0.28 | 0.54 | -0.10 | 0.68 |
| REVENU‡ | 0.88 | -0.19 | 0.85 | -0.24 | 0.84 | -0.22 | -0.26 | 0.81 | -0.24 | 0.80 |
| SEULES§ | 0.13 | 0.80 | -0.12 | 0.82 | 0.03 | 0.87 | 0.82 | -0.03 | 0.87 | -0.07 |
| S_D_V | -0.06 | 0.88 | -0.09 | 0.84 | -0.28 | 0.84 | 0.88 | -0.16 | 0.89 | -0.16 |
| F_MONO# | -0.27 | 0.73 | -0.23 | 0.74 | -0.47 | 0.57 | 0.67 | -0.35 | 0.57 | -0.40 |
| Explained variance | 40% | 33% | 35% | 34% | 35% | 32% | 34% | 31% | 32% | 32% |
| Cumulative variance | 40% | 73% | 35% | 69% | 35% | 67% | 34% | 65% | 32% | 64% |

* Ratio of individuals 15 years and older with no high school diploma to the population 15 years and older

† Ratio of individuals 15 years and older who are employed to the population 15 years and older

‡ Average personal income for the population 15 years and older

§ Ratio of individuals 15 years and older living alone to the population 15 years and older

|| Ratio of individuals 15 years and older who are separated, divorced or widowed to the population 15 years and older

Ratio of single-parent families to the total number of families

NOTE: The above values are saturations. They should be interpreted as correlation coefficients between the indicator and the component. When each component explains essentially the same percentage of the total variance, their position can be inverted.

Source: 2001 Census of Canada.

TABLE 5
General characteristics of the Canadian population by quintile of material and social deprivation

| Deprivation quintile | Population | Age group | | Socio-economic profile | | | | | |
|----------------------------|------------|-------------------|------------------|------------------------|--------------|---------------|--------------|--------------|--------------|
| | n | Under age 15 % | 65 and over % | SCOLAR* % | EMPLOI† % | REVENU‡ \$ | SEULES§ % | S_D_V % | F_MONO# % |
| Material | | | | | | | | | |
| 1 | 5 862 195 | 17.7 | 12.2 | 18.1 | 68.5 | 40 148 | 10.1 | 12.5 | 11.6 |
| 2 | 5 862 218 | 19.4 | 11.6 | 27.0 | 66.0 | 29 658 | 8.3 | 13.0 | 13.5 |
| 3 | 5 862 082 | 19.4 | 12.3 | 32.8 | 63.0 | 26 206 | 8.5 | 13.5 | 15.2 |
| 4 | 5 863 106 | 19.4 | 12.9 | 38.7 | 59.3 | 23 215 | 9.1 | 14.3 | 17.3 |
| 5 | 5 862 500 | 20.4 | 13.0 | 48.7 | 49.0 | 18 542 | 9.6 | 14.6 | 21.5 |
| Social | | | | | | | | | |
| 1 | 5 862 396 | 21.7 | 9.6 | 33.2 | 62.8 | 30 763 | 2.7 | 7.8 | 8.1 |
| 2 | 5 862 428 | 20.7 | 11.2 | 32.9 | 62.6 | 29 038 | 5.2 | 10.9 | 11.2 |
| 3 | 5 861 776 | 19.9 | 12.5 | 33.5 | 61.4 | 27 367 | 7.4 | 13.2 | 14.7 |
| 4 | 5 862 833 | 18.6 | 13.9 | 33.3 | 60.5 | 26 338 | 10.8 | 15.8 | 18.9 |
| 5 | 5 862 668 | 15.5 | 14.9 | 32.4 | 58.5 | 24 261 | 19.7 | 20.2 | 26.3 |
| Material and social | | | | | | | | | |
| 1 & 1 | 1 211 019 | 22.0 | 8.9 | 18.5 | 69.0 | 47 711 | 2.2 | 6.9 | 5.8 |
| 5 & 5 | 1 321 335 | 19.7 | 13.9 | 47.4 | 46.3 | 16 920 | 18.8 | 21.9 | 34.5 |
| Canada | 29 312 101 | 19.3 | 12.4 | 33.1 | 61.2 | 27 554 | 9.1 | 13.6 | 15.8 |

* Ratio of individuals 15 years and older with no high school diploma to the population 15 years and older

† Ratio of individuals 15 years and older who are employed to the population 15 years and older

‡ Average personal income for the population 15 years and older

§ Ratio of individuals 15 years and older living alone to the population 15 years and older

|| Ratio of individuals 15 years and older who are separated, divorced or widowed to the population 15 years and older

Ratio of single-parent families to the total number of families

The values of these characteristics (except for F_MONO) are adjusted according to the age and sex of the Canadian population.

Source: 2001 Census of Canada.

agglomerations (CAs), small towns and rural communities, and the Atlantic region. Conversely, however, the average level of material deprivation is lower in CMAs than in small towns and rural communities, and the Atlantic region.

Deprivation and premature mortality in Canada

Approximately 94% of premature deaths in 2001 were given a deprivation index, for a total of 85 614 deaths (Table 7). Of the deaths that were not given a deprivation index ($n = 5\ 625$), 14% were the result of erroneous postal codes and 86% were the result of DAs with no index corresponding to institutionalized populations.

The adjusted premature mortality rate in 2001, 310 deaths per 100 000, progresses in line with both material and social deprivation (Figure 1). The mortality ratio between material and social deprivation

groups at extreme ends of the spectrum is 2.41 and the difference in mortality is 302 deaths per 100 000, a value equivalent to that observed for Canada as a whole.

While such discrepancies can be seen everywhere in Canada, their magnitude varies enormously by geographic area and region. Accordingly, among the most deprived individuals in Canada, we find that those who live in CAs as well as in small towns and rural communities have the highest rates of premature death (Figure 2). Conversely, in small towns and rural communities, the relative and absolute discrepancies in the mortality rate (ratio and difference) according to deprivation are relatively low (Figure 3). In terms of the regions of Canada, the greatest disparities in mortality according to deprivation are found in the Prairies and in British Columbia, whereas at the CMA level, they are seen in Vancouver and in the

"other CMAs" group. Of the three major Canadian CMAs, Toronto has the smallest disparities.

Discussion

The deprivation index comprises six indicators grouped into two components, material deprivation and social deprivation. These two components occur nationwide, in rural settings and in all the various urban settings (large CMAs, other CMAs and CAs). They point to major socio-economic inequalities in income, education, employment and family structure everywhere, demonstrating the relevance and applicability of the index beyond the urban settings that are usually preferred for the production of geographic proxies.^{9,11-15,33,35}

Variations in the deprivation index are closely linked to variations in premature mortality. Material and social deprivation

TABLE 6
Socio-economic discrepancies by geographic area and region of Canada
Ratio* of most to least deprived persons (material and social) and average value (A)

| Geographic area/ region | Socio-economic characteristics | | | | | | | | | | | |
|-----------------------------------|--------------------------------|--------|---------------------|--------|---------------------|---------|---------------------|--------|---------------------|--------|----------------------|--------|
| | SCOLAR [†] | | EMPLOI [†] | | REVENU [‡] | | SEULES [§] | | S_D_V | | F_MONO ^{**} | |
| | Ratio | A % | Ratio | A % | Ratio | A \$ | Ratio | A % | Ratio | A % | Ratio | A % |
| Toronto CMA | 2.5 | 29.0 | 1.4 | 64.3 | 3.3 | 32 812 | 15.1 | 6.8 | 3.6 | 11.7 | 7.9 | 16.4 |
| Montréal CMA | 3.9 | 29.4 | 1.5 | 60.5 | 2.8 | 26 730 | 9.7 | 11.9 | 2.7 | 15.5 | 6.1 | 18.3 |
| Vancouver CMA | 2.5 | 27.3 | 1.4 | 61.2 | 2.9 | 28 883 | 9.5 | 9.5 | 3.5 | 13.0 | 5.3 | 15.4 |
| Other CMAs | 2.6 | 29.7 | 1.4 | 63.7 | 2.8 | 28 879 | 11.3 | 9.6 | 3.6 | 13.6 | 6.9 | 16.3 |
| CAs | 2.1 | 36.1 | 1.5 | 58.9 | 2.1 | 25 792 | 6.8 | 9.8 | 3.0 | 15.0 | 4.9 | 16.3 |
| Small towns, rural communities | 1.9 | 42.8 | 2.0 | 57.0 | 2.0 | 23 108 | 2.7 | 8.3 | 2.2 | 12.9 | 6.3 | 13.1 |
| Atlantic | 2.5 | 39.2 | 1.8 | 52.8 | 2.4 | 22 713 | 3.4 | 8.2 | 2.4 | 13.4 | 5.5 | 16.2 |
| Quebec | 3.4 | 32.7 | 1.5 | 58.6 | 2.5 | 25 035 | 8.0 | 11.5 | 2.4 | 15.5 | 4.9 | 16.8 |
| Ontario | 2.5 | 31.5 | 1.4 | 62.9 | 2.7 | 30 487 | 10.8 | 7.9 | 3.4 | 12.9 | 6.8 | 15.3 |
| Prairies | 2.5 | 36.2 | 1.4 | 66.0 | 2.7 | 26 931 | 11.7 | 8.5 | 3.4 | 12.2 | 8.1 | 15.3 |
| British Columbia | 2.5 | 30.6 | 1.4 | 59.4 | 2.4 | 27 306 | 7.2 | 9.7 | 3.3 | 14.3 | 5.3 | 15.7 |
| Canada | 2.6 | 33.1 | 1.5 | 61.2 | 2.8 | 27 554 | 8.5 | 9.1 | 3.2 | 13.6 | 5.9 | 15.8 |

* Ratio of the most deprived group (material and social) (Q5 and Q5) and the least deprived (Q1 and Q1). For SCOLAR, SEULES, S_D_V and F_MONO, ratio: Q5 and Q5/Q1 and Q1.
For EMPLOI and REVENU, ratio: Q1 and Q1/Q5 and Q5.

† Ratio of individuals 15 years and older with no high school diploma to the population 15 years and older

‡ Ratio of individuals 15 years and older who are employed to the population 15 years and older

§ Average personal income for the population 15 years and older

|| Ratio of individuals 15 years and older living alone to the population 15 years and older

** Ratio of individuals 15 years and older who are separated, divorced or widowed to the population 15 years and older

** Ratio of single-parent families to the total number of families

The ratios and averages (except for F_MONO) are adjusted for the age and sex of the population in the area or region in question.

Source: 2001 Census of Canada.

contribute independently to mortality, and this contribution increases gradually with the level of deprivation (Figure 1). Such gradients can be observed everywhere in Canada, including in large CMAs and other geographic areas, and in all regions. (Data not presented, available upon request.) Thus, deprivation not only affects groups that are extremely deprived: it is a matter of concern for the entire population.

The combined effect of the two forms of deprivation can be observed by comparing the mortality of groups at the extreme ends of social and material deprivation – Q5Q5 vs. Q1Q1 (Figure 2 and Figure 3). The combined effect is also observable—although in a less marked fashion—in populations whose size is similar to that of populations considered for each dimension separately, that is, on a quintile basis. Hence, in Canada, the mortality rate

ratio and rate difference between extreme quintiles (Q5 vs. Q1) were, respectively, 1.82 (95% CI, 1.73-1.92) and 192 deaths per 100 000 (95% CI, 174-210) when both dimensions of deprivation are considered simultaneously, as opposed to 1.50 (95% CI, 1.45-1.55) and 125 deaths (95% CI, 115-136) for the material dimension and 1.65 (95% CI, 1.60-1.70) and 161 deaths (95% CI, 151-172) for the social dimension, treated separately. Similar differences can be seen in the various geographic settings. (Data available upon request.)

Other studies have already identified social disparities in mortality in Canadian CMAs.^{9,12} This study shows that these inequalities extend to all geographic areas that reflect Canada's diversity. Due to different study methodologies and due to the absence of research on the geography of social disparities in health—in Canada and

internationally—it is difficult to compare these results with those obtained elsewhere. In fact, the deprivation index sheds new light on the social disparities in health in Canada by expressing their variability by geographic area.

These initial results on premature mortality require further study, either to identify the exact causes of death, to determine if there is a difference in effect on sex, or to decipher the underlying factors. For instance, it would be interesting to explore factors such as relative deprivation,⁷² the presence of Aboriginal people,⁷³ recent immigration,⁷⁴ and the risks associated with the use of geographic proxies.⁷⁵ The use of such proxies may explain, at least in part, the presence of weak ratios and differences in mortality in small towns and rural communities. These initial results could also be compared to those generated with

TABLE 7
Population and deaths in persons under age 75 by geographic area,
region, and quintile of material and social deprivation, Canada, 2001

| | Population Number | Deaths Number |
|--|----------------------|------------------|
| Geographic area | | |
| Toronto CMA | 4 384 015 | 10 514 |
| Montréal CMA | 3 164 585 | 9 634 |
| Vancouver CMA | 1 837 025 | 4 632 |
| Other CMAs | 8 491 360 | 24 811 |
| CAs | 4 178 475 | 14 744 |
| Small towns, rural communities | 5 705 250 | 21 279 |
| Region of Canada | | |
| Atlantic | 2 123 610 | 7 359 |
| Quebec | 6 711 995 | 22 298 |
| Ontario | 10 554 165 | 31 377 |
| Prairies | 4 692 225 | 13 706 |
| British Columbia | 3 588 725 | 10 568 |
| Material deprivation | | |
| Quintile 1 | 5 545 815 | 13 541 |
| Quintile 2 | 5 573 520 | 15 176 |
| Quintile 3 | 5 557 830 | 16 765 |
| Quintile 4 | 5 536 780 | 18 470 |
| Quintile 5 | 5 546 765 | 21 662 |
| Social deprivation | | |
| Quintile 1 | 5 662 775 | 13 381 |
| Quintile 2 | 5 613 635 | 15 370 |
| Quintile 3 | 5 557 085 | 16 871 |
| Quintile 4 | 5 490 310 | 18 197 |
| Quintile 5 | 5 436 905 | 21 795 |
| Material and social deprivation | | |
| Quintile 1 and Quintile 1 | 1 172 970 | 2 277 |
| Quintile 5 and Quintile 5 | 1 237 555 | 6 123 |
| Canada | 27 760 710 | 85 614 |

Source: Census and mortality database, 2001.

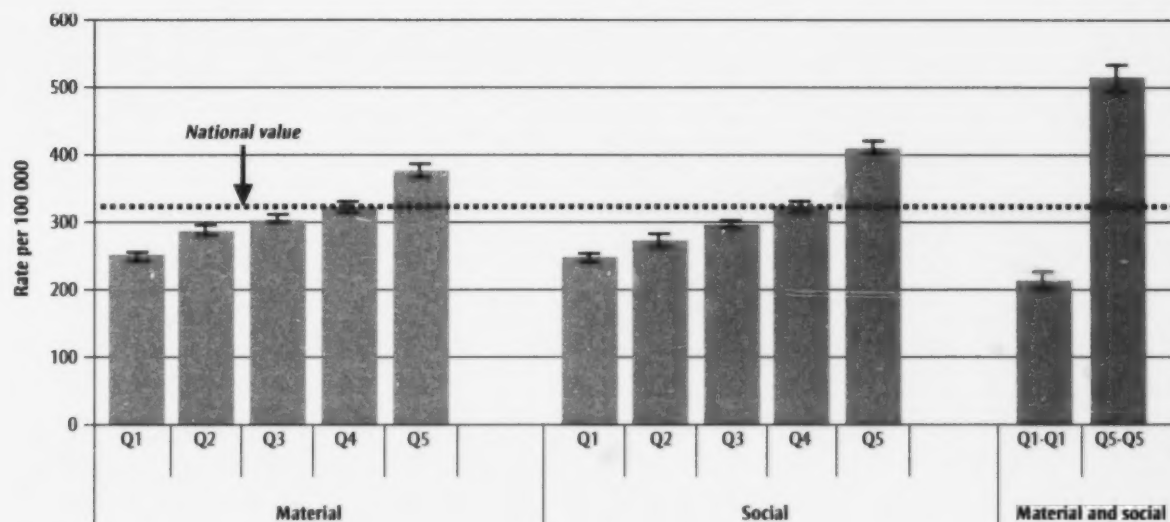
respect to other socio-economic indicators, such as low income. In order to be useful and correctly carried out, however, such a comparison should consider several socio-economic and health indicators simultaneously, with due attention paid to their conceptual foundations and their performance in relation to technical and political criteria,^{5,7,20,21,28,35,51,76-78} an exercise that is well beyond the framework of this study.

The deprivation index has its limitations. It is not an individual measure of socio-economic conditions, but rather a measure of the conditions seen at the neighbourhood level. The index could be used in an etiological analysis, but it cannot replace an individual measure, which is the only way of portraying individual or family education, for example. Therefore, in an etiological analysis, these two types of measures should be considered simultaneously, through multilevel modelling.⁷⁹ This is now possible thanks to a new file combining a sample from the 1991 Census of Canada with mortality data from 1991 to 2001.⁸⁰

Combating social inequalities in health has become a major challenge for health systems, both in Canada⁸¹ and around the world.⁸² The availability of tools to measure inequalities is a prerequisite to any planning to reduce them. In Quebec, the deprivation index is now used at every stage of the health planning process, including the measurement and monitoring of inequalities,^{36-38,42,43} the development of strategic goals,⁸³ the evaluation of both provincial and local services^{40,44} and resource allocation to the regions.⁸⁴

A recent study by the Canadian Institute for Health Information (CIHI)⁸⁵ demonstrated the existence of clear gradients in hospital admissions and in self-reported health in 15 CMAs, based on this deprivation index. The relevance and usefulness of a measure often become apparent only when the measure is put to use. The Canadian index of material and social deprivation is therefore available for trial by researchers and managers in the health sector. It is also associated with a variety of products now available on the *Institut national de santé publique du Québec* (INSPQ) website.⁸⁶

FIGURE 1
Premature mortality rate by quintile of material and social deprivation Canada, 2001



NOTE: Death rates are adjusted for age, sex, geographic area and the other forms of deprivation.

Source: 2001 Census of Canada; Statistics Canada, 2001 Canadian Mortality Database.

Acknowledgements

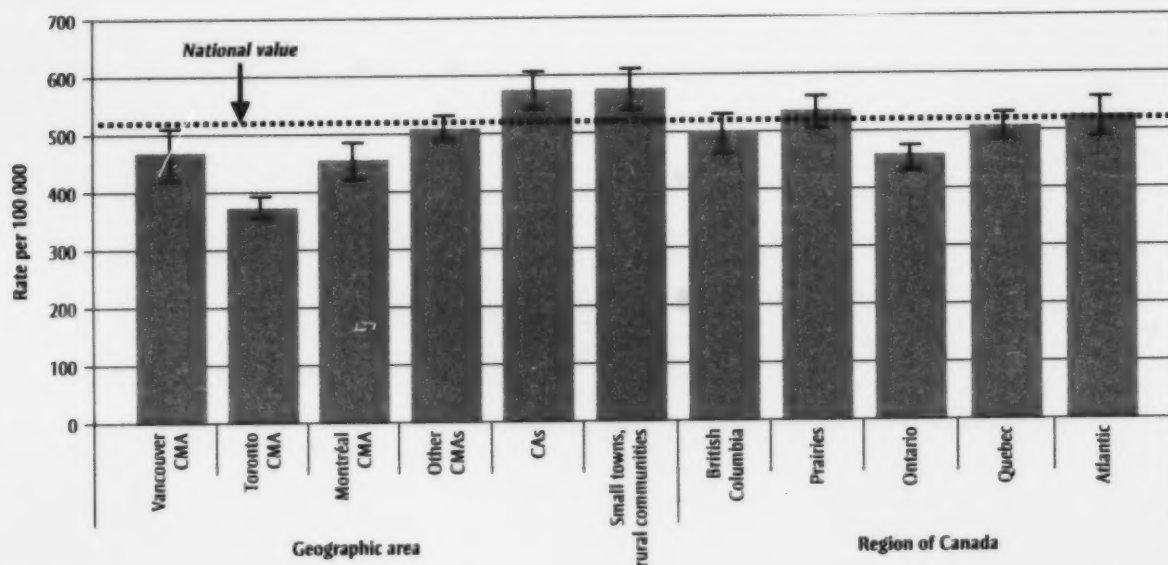
We would like to thank Russell Wilkins of Statistics Canada for facilitating access to the Canadian Mortality Data. However, analysis of these data and the opinions expressed in this text are not those of Statistics Canada. We would also like to thank Robert Choinière of the *Institut national de santé publique du Québec*, as well as two anonymous reviewers, for their input on the initial version of this text.

References

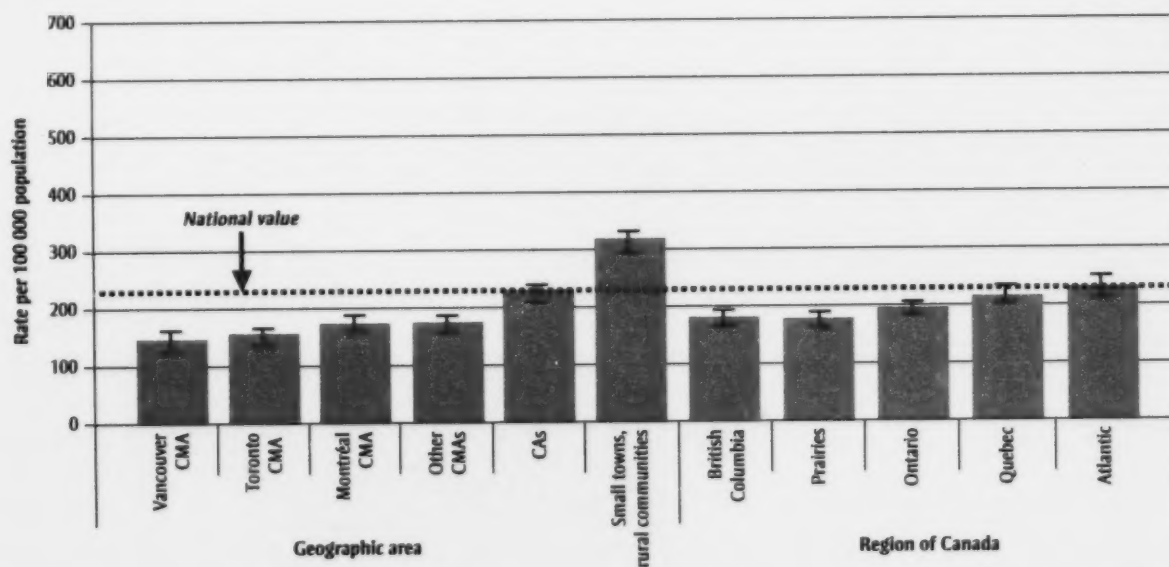
1. Canadian Institute for Health Information. The Health Indicators Project: The next 5 years. Report from the Second Consensus Conference on Population Health Indicators. Ottawa (ON): Statistics Canada; 2005.
2. Statistics Canada (Health Division). A review of national health surveys in Canada, 1978-1987. In: Health Reports-Prototype. Ottawa; 1988. p. 28-50. Cat. No. 82-003-XPE.
3. Swain L, Catlin G, Beaudet MP. The National Population Health Survey—its longitudinal nature. *Health Rep.* 1999;10(4):69-82.
4. Statistics Canada. Canadian Community Health survey profiles 2003 [Internet]. Ottawa (ON): Statistics Canada; [modified 2005 Jun 30]. Available from: <http://www.statcan.gc.ca/pub/82-576-x/82-576-x2005001-eng.htm>.
5. Gordon D. Area-based deprivation measures: A U.K. perspective. In: Kawachi I, Berkman L, editors. *Neighborhoods and health*. New York: Oxford University Press; 2003. p. 179-210.
6. Kunst AE, Mackenbach JP. *Measuring socioeconomic inequalities in health*. Copenhagen: World Health Organization; 1994.
7. Krieger N, Chen JT, Waterman PD, Soobader MJ, Subramanian SV, Carson R. Geocoding and monitoring of US socioeconomic inequalities in mortality and cancer incidence: does the choice of area-based measure and geographic level matter?: the Public Health Disparities Geocoding Project. *Am J Epidemiol.* 2002 Sep 1;156(5):471-82.
8. Krieger N, Williams DR, Moss NE. Measuring social class in US public health research: concepts, methodologies, and guidelines. *Annu Rev Public Health.* 1997;18:341-78.
9. Choinière R. Évolution des disparités de la mortalité selon le revenu à Montréal. *Journées annuelles de santé publique*, editor. 2002. Unpublished Work.
10. Mustard CA, Derksen S, Berthelot JM, Wolfson M. Assessing geographic proxies for household income: a comparison of household and neighbourhood level income measures in the study of population health status. *Health Place.* 1999 Jun;5(2):157-71.

FIGURE 2
Premature mortality rate in the most and least deprived persons (material and social) by geographic area and region of Canada, 2001

MOST DEPRIVED PERSONS



LEAST DEPRIVED PERSONS

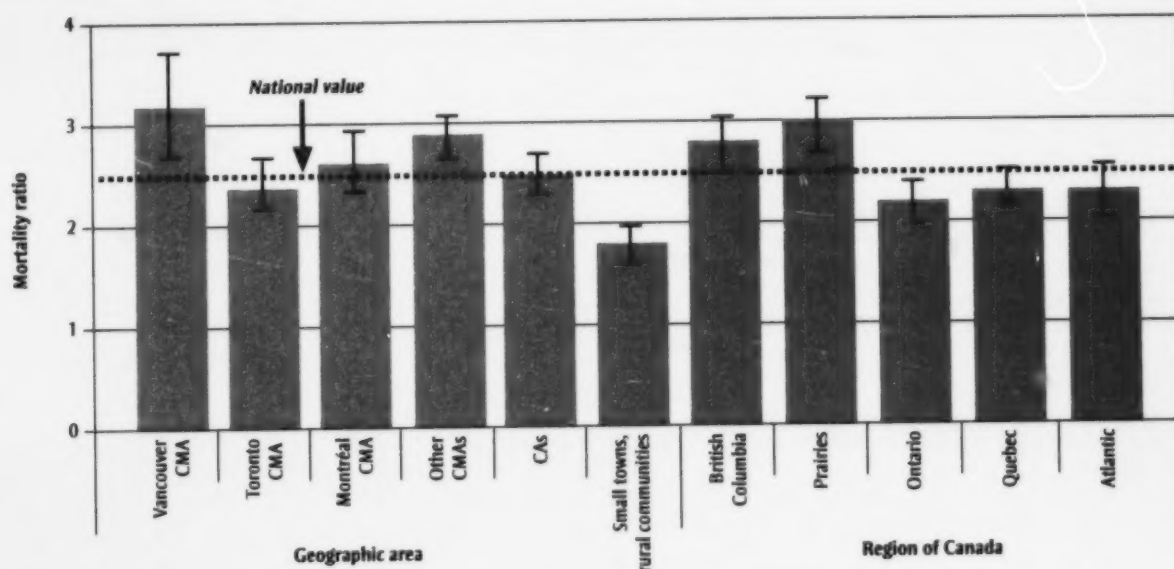


NOTE: The rates are adjusted for age, sex and, in the case of regions of Canada, geographic area.

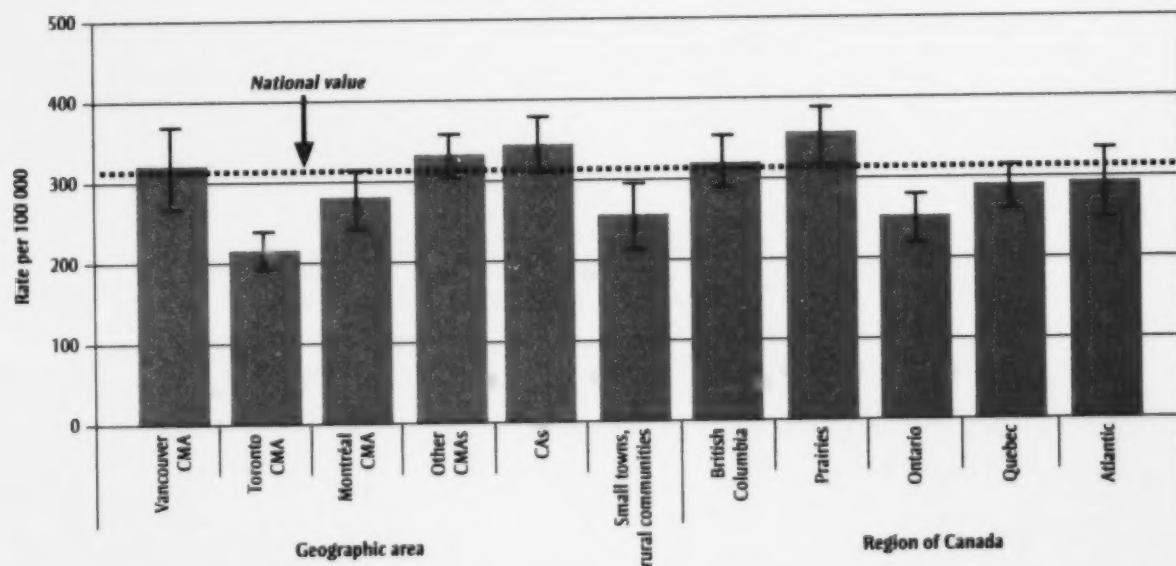
Source: 2001 Census of Canada; Statistics Canada, 2001 Canadian Mortality Database.

FIGURE 3
Ratio and difference in premature mortality between the most and least deprived persons (material and social) by geographic area and region of Canada, 2001

MORTALITY RATIO



MORTALITY DIFFERENCE



NOTE: Rates are adjusted for age, sex and, in the case of regions of Canada, geographic area.

Source: 2001 Census of Canada; Statistics Canada, 2001 Canadian Mortality Database.

11. Roos NP, Mustard CA. Variation in health and health use by socioeconomic status in Winnipeg, Canada: does the system work well? Yes and no. *Milbank Q.* 1997;75(1): 89-111.
12. Wilkins R, Berthelot JM, Ng E. Trends in mortality by neighbourhood income in urban Canada from 1971 to 1996. *Health Rep, Supplement*;2002;13:1-28.
13. Wilkins R, Ng E, Berthelot JM, Mayer F. Provincial differences in disability-free life expectancy by neighbourhood income and education in Canada, 1996. Ottawa (ON): Statistics Canada; 2002. Unpublished Work.
14. Marmot M, Wilkinson RG, editors. *Social Determinants of Health*. 2nd ed. Copenhagen: World Health Organization; 2003.
15. Leclerc A, Fassin D, Grandjean H, Kaminski M, Lang T. *Les inégalités sociales de santé*. Paris: Éditions La Découverte et Syros; 2000.
16. Adams J, Ryan V, White M. How accurate are Townsend Deprivation Scores as predictors of self-reported health? A comparison with individual level data. *J Public Health (Oxf)*. 2005 Mar;27(1):101-6.
17. Carstairs V, Morris R. Deprivation: explaining differences in mortality between Scotland and England and Wales. *BMJ*. 1989 Oct 7;299(6704):886-9.
18. Carstairs V. Deprivation indices: their interpretation and use in relation to health. *J Epidemiol Community Health*. 1995 Dec;49 Suppl 2:S3-S8.
19. Jarman B. Identification of underprivileged areas. *Br Med J (Clin Res Ed)*. 1983 May 28; 286(6379):1705-9.
20. Jarman B, Townsend P, Carstairs V. Deprivation indices. *BMJ*. 1991 Aug 31;303(6801):523.
21. Morris R, Carstairs V. Which deprivation? A comparison of selected deprivation indexes. *J Public Health Med*. 1991 Nov;13(4):318-26.
22. Noble M, McLennan D, Wilkinson K, Whitworth A, Barnes H. *The English Indices of Deprivation 2007*. London (UK): Department for Communities and Local Government Publications; 2008.
23. Townsend P, Phillimore P, Beattie A. *Health and Deprivation: Inequalities and the North*. London: Croom Helm; 1988.
24. Bajekal M, Jan S, Jarman B. The Swedish UPA score: an administrative tool for identification of underprivileged areas. *Scand J Soc Med*. 1996 Sep;24(3):177-84.
25. Tello JE, Jones J, Bonizzato P, Mazzi M, Amadeo F, Tansella M. A census-based socio-economic status (SES) index as a tool to examine the relationship between mental health services use and deprivation. *Soc Sci Med*. 2005 Nov;61(10):2096-105.
26. Benach J, Yasui Y, Borrell C, Pasarin MI, Martinez JM, Daponte A. The public health burden of material deprivation: excess mortality in leading causes of death in Spain. *Prev Med*. 2003 Mar;36(3):300-8.
27. Chailier B, Viel JF. Relevance and validity of a new French composite index to measure poverty on a geographical level. *Rev Epidemiol Santé Publique*. 2001 Feb; 49(1):41-50.
28. Krieger N, Chen JT, Waterman PD, Soobader MJ, Subramanian SV, Carson R. Choosing area based socioeconomic measures to monitor social inequalities in low birth weight and childhood lead poisoning: The Public Health Disparities Geocoding Project (US). *J Epidemiol Community Health*. 2003 Mar; 57(3):186-99.
29. Hogan JW, Tchernis R. Bayesian factor analysis for spatially correlated data, with application to summarizing area-level material deprivation from census data. *J Am Stat Assoc*. 2004 Jun 1;99(466):314-24.
30. Kunst AE. Commentary: Using geographical data to monitor socioeconomic inequalities in mortality: experiences from Japanese studies. *Int J Epidemiol*. 2005 Feb; 34(1):110-2.
31. Salmond C, Crampton P, Sutton F. NZDep91: A New Zealand index of deprivation. *Aust N Z J Public Health*. 1998 Dec;22(7):835-7.
32. Frohlich N, Mustard C. A regional comparison of socioeconomic and health indices in a Canadian province. *Soc Sci Med*. 1996 May;42(9):1273-81.
33. Matheson FI, Moineddin R, Dunn JR, Creatore MI, Gozdyra P, Glazier RH. Urban neighborhoods, chronic stress, gender and depression. *Soc Sci Med*. 2006 Nov;63(10):2604-16.
34. Pampalon R, Raymond G. A deprivation index for health and welfare planning in Quebec. *Chronic Dis Can*. 2000;21(3):104-13.
35. Schuurman N, Bell N, Dunn JR, Oliver L. Deprivation indices, population health and geography: an evaluation of the spatial effectiveness of indices at multiple scales. *J Urban Health*. 2007 Jul;84(4):591-603.
36. Dupont MA, Pampalon R, Hamel D. Deprivation and cancer mortality Among Quebec Women and Men, 1994-1998. Québec (QC). Institut national de santé publique du Québec. 2004.
37. Hamel D, Pampalon R. Trauma and deprivation in Québec. Québec (QC). Institut national de santé publique du Québec; 2002.
38. Martinez J, Pampalon R, Hamel D. Deprivation and stroke mortality in Quebec. *Chronic Dis Can*. 2003 Spring-Summer; 24(2-3):57-64.
39. Pampalon R, Rochon M. Health Expectancy and Deprivation in Québec, 1996-1998. Paper presented at: 13th Annual Meeting of the International Network on Health Expectancies (REVES), Vancouver (BC).
40. Pampalon R, Raymond G. Indice de défavorisation matérielle et sociale: son application au secteur de la santé et du bien-être. *Santé, Société et Solidarité*. 2003;(1):191-208.

41. Pampalon R, Philibert M, Hamel D. Inégalités sociales et services de proximité au Québec: Développement d'un système d'évaluation issu d'une collaboration entre chercheurs et intervenants. *Santé, Société et Solidarité*. 2004;(2):73-88.
42. Pampalon R, Hamel D, Gamache P. Évolution récente de la mortalité prématurée au Québec selon la défavorisation matérielle et sociale. In: Frohlich K, De Koninck M, Bernard P, Demers A, editors. *Les inégalités sociales de santé au Québec*. Montréal (QC): Les Presses de l'Université de Montréal; 2008.
43. Pampalon R, Hamel D, Gamache P. Recent changes in the geography of social disparities in premature mortality in Québec. *Soc Sci Med*. 2008 Oct;67(8):1269-1281.
44. Philibert M, Pampalon R, Hamel D, Thouez JP, Loiseleur C. Material and social deprivation and health and social services utilisation in Québec: a local-scale evaluation system. *Soc Sci Med*. 2007; 64:1651-64.
45. Ministère de la Santé et des Services sociaux du Québec [Ministry of Health and Social Services, Quebec]. *Variations nationales de l'indice de défavorisation en 2001*. [Internet]. [Québec (QC)]: Ministère de la Santé et des Services sociaux du Québec; 2009. Available from: http://www.msss.gouv.qc.ca/statistiques/atlas/atlas/index.php?id_carte=11
46. Townsend P. Deprivation. *J Soc Pol*. 1987 Apr;16:125-46.
47. Wagle U. Rethinking poverty: definition and measurement. *Int Soc Sci J*. 2002; 54(1/171):155-65.
48. Congdon P. The epidemiology of suicide in London. *J Roy Stat Soc Ser A Sta*. 1996;159:515-33.
49. Curtis S, Copeland A, Fagg J, Congdon P, Almog M, Fitzpatrick J. The ecological relationship between deprivation, social isolation and rates of hospital admission for acute psychiatric care: a comparison of London and New York City. *Health Place*. 2006 Mar;12(1):19-37.
50. Statistics Canada. 2001 Census Dictionary. Ottawa (ON): Statistics Canada; 2003.
51. Krieger N, Zierler S, Hogan JW, Waterman P, Chen J, Lemieux K, Gjelsvik A. Geocoding and Measurement of Neighborhood socioeconomic Position: A U.S. Perspective. In: Kawachi I, Berkman L, editors. *Neighborhoods and Health*. New York: Oxford University Press; 2003. p. 147-78.
52. Niggebrugge A, Haynes R, Jones A, Lovett A, Harvey I. The index of multiple deprivation 2000 access domain: a useful indicator for public health? *Soc Sci Med*. 2005 Jun;60(12):2743-53.
53. Muecke C, Hamel D, Bouchard C, Martinez J, Pampalon R, Choinière R. Doit-on utiliser la standardisation directe ou indirecte dans l'analyse de la mortalité à l'échelle des petites unités géographiques? Québec (QC): Institut national de santé publique du Québec; 2005.
54. Gilthorpe MS. The importance of normalisation in the construction of deprivation indices. *J Epidemiol Community Health* 1995 Dec;49 Suppl 2:S45-S50.
55. Index 99 Team. Index of Deprivation 1999 Review. Final consultation. Report for Formal Consultation. Stage 2: Methodology for an Index of Multiple Deprivation. Oxford: University of Oxford; 1999.
56. Barnett S, Roderick P, Martin D, Diamond I, Wrigley H. Interrelations between three proxies of health need at the small area level: an urban/rural comparison. *J Epidemiol Community Health*. 2002 Oct; 56(10):754-61.
57. Barnett S, Roderick P, Martin D, Diamond I. A multilevel analysis of the effects of rurality and social deprivation on premature limiting long term illness. *J Epidemiol Community Health*. 2001 Jan;55(1):44-51.
58. Martin D, Brigham P, Roderick P, Barnett S, Diamond I. The (mis)representation of rural deprivation. *Environ Plann A*. 2000; 32:735-51.
59. Gilthorpe MS, Wilson RC. Rural/urban differences in the association between deprivation and healthcare utilisation. *Soc Sci Med*. 2003 Dec;57(11):2055-63.
60. Haynes R, Gale S. Deprivation and poor health in rural areas: inequalities hidden by averages. *Health Place*. 2000 Dec; 6(4):275-85.
61. Davey-Smith G, Dorling D, Mitchell R, Shaw M. Health inequalities in Britain: continuing increases up to the end of the 20th century. *J Epidemiol Community Health*. 2002 Jun;56:434-5.
62. James PD, Wilkins R, Detsky AS, Tugwell P, Manuel DG. Avoidable mortality by neighbourhood income in Canada: 25 years after the establishment of universal health insurance. *J Epidemiol Community Health*. 2007 Apr;61(4):287-96.
63. Leclerc A, Chastang JF, Menvielle G, Luce D. Socioeconomic inequalities in premature mortality in France: have they widened in recent decades? *Soc Sci Med*. 2006 Apr; 62(8):2035-45.
64. Mackenbach JP, Bos V, Andersen O, Cardano M, Costa G, Harding S, Reid A, Hemström O, Valkonen T, Kunst AE. Widening socioeconomic inequalities in mortality in six Western European countries. *Int J Epidemiology*. 2003;32:830-7.
65. Singh GK, Siahpush M. Increasing inequalities in all-cause and cardiovascular mortality among US adults aged 25-64 years by area socioeconomic status, 1969-1998. *Int J Epidemiol*. 2002 Jun;31:600-13.
66. Turrell G, Mathers C. Socioeconomic inequalities in all-cause and specific-cause mortality in Australia: 1985-1987 and 1995-1997. *Int J Epidemiol*. 2001;30:231-9.
67. Allison PD. *Logistic regression using SAS system: theory and application*. North Carolina: SAS Institute Inc.; 1999.
68. Tiwari HK, Elston RC. The approximate variance of a function of random variables. *Biometrical J*. 1999;41(3):351-7.

69. Boström C, Rosén M. Measuring social inequalities in health: politics or science? *Scand J Public Health*. 2003;31:211-5.
70. Regidor E. Measures of health inequalities: part 1. *J Epidemiol Community Health*. 2004;58:858-61.
71. Regidor E. Measures of health inequalities: part 2. *J Epidemiol Community Health*. 2006;58:900-3.
72. Wilkinson RG, Pickett KE. Income inequality and population health: a review and explanation of the evidence. *Soc Sci Med*. 2006 Apr;62(7):1768-84.
73. Health Canada. Healthy Canadians: A federal report on comparable health indicators 2004. Ottawa (ON): Health Canada; 2004.
74. Chen J, Ng E, Wilkins R. The health of Canada's immigrants in 1994-95. *Health Rep*. 1996;7(4):33-50.
75. Wilkins R. Neighbourhood income quintiles derived from Canadian postal codes are apt to be misclassified in rural but not urban areas. Ottawa (ON): Statistics Canada; 2004. Unpublished Work.
76. Ellaway A. Are single indicators of deprivation as useful as composite indicators in predicting morbidity and mortality: results from the Central Clydeside Conurbation. *Health Bull (Edinb)*. 1997 Sep;55(5):283-4.
77. Gordon D. Census based deprivation indices: their weighting and validation. *J Epidemiol Community Health*. 1995 Dec;49 Suppl 2:S39-S44.
78. Carr-Hill R, Chalmers-Dixon P. The public health observatory handbook of health inequalities measurement. Oxford: South East Public Health Observatory; 2005.
79. Subramanian SV, Jones K, Duncan C. Multilevel Methods for Public Health Research. In: Kawachi I, Berkman L, editors. *Neighborhoods and Health*. New York: Oxford University Press; 2003. p. 65-111.
80. Wilkins R. Linking two of Canada's national treasures: mortality follow-up from a census-based sample of the Canadian population. Paper presented at: Annual Meeting of the Canadian Population Society. Congress of the Humanities and Social Sciences; 2005 May 31-Jun 1; London (ON).
81. Butler-Jones D. The Chief Public Health Officer's report on the state of public health in Canada in 2008: addressing health inequalities. Ottawa (ON): Public Health Agency of Canada; 2008. Cat. No.: HP2-10/2008E.
82. Commission on social determinants of health. Closing the gap in a generation. Health equity through action on the social determinants of health. Geneva: World Health Organization; 2008.
83. Ministère de la Santé et des Services sociaux du Québec. Troisième rapport national sur l'état de santé de la population du Québec. Riches de tous nos enfants: La pauvreté et ses repercussions sur la santé des jeunes de moins de 18 ans. Québec (QC): La directions des communications du ministère de la Santé et des Services sociaux du Québec; 2007.
84. Ministère de la Santé et des Services sociaux du Québec. Nouveau mode d'allocation des ressources 2007-2008. Québec (QC): Direction de l'allocation des ressources, MSSS; 2007. Unpublished Work.
85. Canadian Institute for Health Information. Reducing gaps in health: a focus on socio-economic status in urban Canada. Ottawa (ON): Canadian Institute for Health Information; 2008.
86. Institut national de santé publique du Québec. Indice canadien de défavorisation. [Internet]. Québec (QC): Institut national de santé publique du Québec; 2008. Available from: <http://www.inspq.qc.ca/santescope/liens.asp?comp=9&nav=M>

Report summary

Tracking heart disease and stroke in Canada 2009

S. Dai(1); C. Bancej(1); A. Bienek(1); P. Walsh(1); P. Stewart(1); A. Wielgosz(1)

Introduction

Tracking Heart Disease and Stroke in Canada 2009 provides the most current and comprehensive picture of cardiovascular diseases (CVD), including heart diseases and stroke, in Canada. Written in collaboration with the Canadian Institute for Health Information (CIHI), Canadian Stroke Network (CSN), Heart and Stroke Foundation of Canada and Statistics Canada, it is the first report on CVD surveillance to be published by the Public Health Agency of Canada.

The main purpose of the report is to provide the Canadian government and CVD stakeholders with current knowledge to enable policy making decisions that improve the outcome of these diseases, and to increase the awareness of Canadians so that they can act to reduce their risk of developing CVD. The information presented in the report complements the Canadian Heart Health Strategy and Action Plan (CHHS-AP), which recommends increased gathering and dissemination of national data on CVD.

The report covers a broad range of topics, including the current prevalence and hospitalization and mortality rates of heart disease and stroke, the economic impact of CVD, the major risk factors and prevention. It also compares CVD rates between provinces and highlights health inequalities.

The report shows that, while mortality rates have declined, risk factors remain widespread, with nine in ten Canadians having at least one risk factor for CVD.

With the rise in diabetes and obesity and the aging of the Canadian population, CVD rates will likely increase in the future unless preventative action is taken.

Highlights

CVD has a major impact on individuals and their families, with many people reporting fair or poor perceived health and restricted activity levels which necessitated the need for help in daily activities. The development or resurfacing of anxiety disorders and depression associated with CVD may influence coping and health outcomes.

In 2005, overall one in three deaths was from CVD. While most of the deaths were in the older age-group, one in four people aged 45 to 64 years died from CVD. The pattern of mortality rates across the country is similar to the pattern of risk factors, with higher rates of risk factors and mortality for CVD in the Atlantic provinces compared to British Columbia.

In 2005/06, CVD was the most common diagnosis for hospitalization, accounting for 16.9% of all hospitalizations. Further, an estimated 65.7 million prescriptions were dispensed for the treatment of CVD, and Canadians made 34.6 million visits to community physicians (10.3% of all visits) for the management of these diseases. The second largest contributor to total health costs, only slightly behind musculoskeletal conditions, CVD cost Canadians \$22.2 billion in 2000, which

included \$7.6 billion in direct costs and \$14.6 billion in indirect costs.

Stroke

Approximately 300 000 Canadians are living with the effects of stroke. In the 75 plus age group, 7.1% of Canadians reported living with the effects of a stroke. A significant burden is placed on patients who experience stroke, as well as on their families and caregivers and on the healthcare system. More than half of all stroke survivors require some form of formal rehabilitation services.

Mortality rates due to stroke are on the decline and hospitalization rates for acute stroke have decreased since 1995, likely due to a reduction in risk factors and better treatment. In addition, the ability of health care professionals to diagnose stroke has improved significantly over the past twenty years with the increased availability of computed tomography (CT) and magnetic resonance imaging (MRI).

Heart disease

In 2007, 1.3 million Canadians (4.8% of the total population) reported living with heart disease. The proportion was 14.8% among those aged 65 to 74 years, and rose to 22.9% among seniors 75 years and older.

The rates of hospitalization for and deaths from ischemic heart disease and heart attack have been decreasing since 1970, and hospitalization and mortality rates for congestive heart failure have also begun to decrease. Between 1996 and 2005, 1564 heart transplantations and

Author References

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58 re-transplantations were carried out in Canada. Other surgical procedures for heart disease included coronary artery bypass grafting, coronary angioplasties, valve surgery and pacemaker implantation, with more of these surgeries performed on men than on women, particularly in those aged 70 to 79 years, reflecting in part that more men than women have heart disease in this age group.

Key risk factors

A genetic susceptibility, combined with unhealthy behaviours and environment, increases the risk of CVD.

Behavioural risks

The risk of CVD can be greatly reduced by not smoking, by exercising regularly, by managing stress effectively, by eating well and maintaining a healthy weight, and by the early recognition and treatment of high blood pressure, high cholesterol and diabetes. However, unhealthy behaviours which permeate our society continue to put Canadians at risk. According to the 2007 Statistics Canada Canadian Community Health Survey and the 2004 Statistics Canada Nutrition Survey:

- Almost one in six Canadians aged 15 or over smoked every day.
- About half of the population (49.5%) did not follow the recommended guidelines to be physically active for at least 30 minutes per day during leisure time, and this proportion of the population increased with age.
- Over half of the population aged 12 or over (56.2%) reported consuming less than five daily servings of vegetables and fruit, with the highest proportion in the 35 to 44 year age group.
- Of Canadians aged 31 to 50 years, 27.7% ate a high fat diet, consuming more than 35% of their total calories in the form of fat.
- More than half of Canadians aged 18 or more years (51%) reported weight in the overweight or obese range, with the 55 to 64 year age group having the highest proportion of individuals (62.2%) who were overweight or obese.

- Diabetes, a significant risk factor for CVD, was self-reported by 7.1% of adults, with the highest proportion with this condition in the 75 to 84 year age group, where it occurred among 23.6% of men and 19.2% of women. (from 2005 PHAC National Diabetes and Chronic Disease Surveillance System).
- High blood pressure was diagnosed by a health care professional in 18.8% of women and 17.3% of men, and the proportion of the population with this condition increased with age.

Socio-economic inequalities

- Diabetes was four times higher and the prevalence of daily smoking and high blood pressure was about twice as high for women in the lower income quintile compared to women in the highest income quintile.
- Several risk factors, including smoking, physical inactivity during leisure time, inadequate consumption of vegetables and fruits, high blood pressure and diabetes, were more common among both men and women in the lowest income quintile compared to those in the highest income quintile. The opposite was true for being overweight or obese or suffering from stress, which increased with increasing income.

Aboriginal populations

- First Nations adults were more likely to have diabetes, to smoke and to be overweight or obese than the general population.
- Inuit adults also had a much higher proportion of smokers than the general population.
- Individuals who self-identified as Métis were also more likely to smoke and to be overweight or obese compared to the general population.

Summary

This report provides a comprehensive look at progress in preventing CVD and their outcomes. The mortality rate for CVD has been decreasing for the past 30 years, probably due to both improved prevention and improved management. Lower rates of smoking, increased physical activity, healthier diets and better control of hypertension and blood cholesterol have all contributed to reducing the risk of developing heart disease and stroke.

However, we should not be complacent: Canadians still run a high risk of developing CVD. Nine out of ten individuals over the age of 20 years have at least one of the following risk factors: smoking, physical inactivity during leisure time, less than the recommended daily consumption of vegetables and fruit, stress, excess weight or obesity, high blood pressure, or diabetes. Two in five Canadians have three or more of these risk factors. In addition, socio-economic inequalities and high rates of smoking and obesity among First Nations, Inuit and Métis are of concern.

The risk of CVD increases with age, and our population is aging. In addition, we have increasing rates of obesity and diabetes, two conditions that greatly increase the risk of developing CVD. As a result, over the next two decades we expect to see an increase in the number of individuals developing heart disease or stroke among aging baby boomers. This will put a strain on the health care system, compromising the health of Canadians overall, and have a major economic impact. Prevention is the key to reversing this trend.

Tracking Heart Disease and Stroke in Canada 2009 is now available on the Public Health Agency of Canada website at:

<http://www.phac-aspc.gc.ca/publicat/2009/cvd-avc/index-eng.php>

Announcements

International Congress of Nutrition 2009

October 4-9, 2009
Bangkok, Thailand
www.icn2009.com

Cardiometabolic Health Congress 2009

October 7-10, 2009
Boston, Massachusetts, U.S.A.
www.cardiometabolichealth.org

20th World Diabetes Congress

October 18-22, 2009
Montréal, Quebec, Canada
www.idf2009.org

Ontario Public Health Conference

November 1-4, 2009
Toronto, Ontario, Canada
<http://www.ophaconference.ca/>

Canadian Arthritis Network 2009 Annual Scientific Conference

November 19-21, 2009
Vancouver, British Columbia, Canada
www.arthritisnetwork.ca

Journées annuelles de santé publique (JASP)

November 23-26, 2009
Montréal, Quebec, Canada
www.inspq.qc.ca/aspx/fr/jasp_accueil.aspx?sortcode=1.55.58.61.62

European Conference on Public Health 2009

November 26-28, 2009
Lodz, Poland
www.eupha.org/site/upcoming_conference.php

Eighth Annual AACR International Conference on Frontiers in Cancer Prevention Research

December 6-9, 2009
Houston, Texas, U.S.A.
www.aacr.org/home/scientists/meetings--workshops/frontiers-in-cancer-prevention-research.aspx

World Congress on Controversies in Cardiovascular Diseases 2010

February 18-21, 2010
Istanbul, Turkey
www.comtecmed.com/ccare/2010

International Conference on Early Disease Detection and Prevention 2010

February 25-28, 2010
Munich, Germany
www.paragon-conventions.com/eddp2010

Joint Conference - 50th Cardiovascular Disease, Epidemiology and Prevention/ Nutrition, Physical Activity and Metabolism, 2010

March 2-6, 2010
San Francisco, California, U.S.A.
www.americanheart.org/presenter.jhtml?identifier=3065525

Third International Conference on Hypertension, Lipids, Diabetes, and Stroke Prevention

March 4-6, 2010
Berlin, Germany
www.kenes.com/strokeprevention

20th IUHPE World Conference on Health Promotion and Health Education

July 11-15, 2010
Geneva, Switzerland
www.iuhpeconference.net

International Congress on Obesity 2010

July 11-16, 2010
Stockholm, Sweden
www.ico2010.org

World Congress on Heart Disease

July 24-27, 2010
Vancouver, British Columbia, Canada
www.cardiologyonline.com

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Chronic Diseases in Canada (CDIC) is a quarterly scientific journal focussing on the prevention and control of non-communicable diseases and injuries in Canada. Its feature articles are peer reviewed. The content of articles may include research from such fields as epidemiology, public/community health, biostatistics, the behavioural sciences, and health services or economics. CDIC endeavours to foster communication on chronic diseases and injuries among public health practitioners, epidemiologists and researchers, health policy planners and health educators. Submissions are selected based on scientific quality, public health relevance, clarity, conciseness and technical accuracy. Although CDIC is a publication of the Public Health Agency of Canada, contributions are welcomed from both the public and private sectors. Authors retain responsibility for the contents of their papers, and opinions expressed are not necessarily those of the CDIC editorial committee nor of the Public Health Agency of Canada.

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Workshop/Conference Report: Summarize significant, recently held events relating to national public health (maximum 1,200 words). Abstract not required.

Cross-Canada Forum: For authors to present or exchange information and opinions on regional or national surveillance findings, programs under development or public health policy initiatives (maximum 3,000 words). Abstract not required.

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Cover letter: Signed by all authors, stating that all have seen and approved the final manuscript and have met the authorship including a full statement regarding any prior or duplicate publication or submission for publication.

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Second title page: Title only; start page numbering here as page 1.

Abstract: Unstructured (one paragraph, no headings), maximum 175 words (100 for short reports); include 3B8 key words (preferably from the Medical Subject Headings (MeSH) of Index Medicus).

Text: Double-spaced, 1 inch (25 mm) margins, 12 point font size.

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